The Role of Data Supported Decision-Making Technology in Respiratory Care

Helena Tendedez

School of Computing and Communications,

Lancaster University

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Dedicated to every cat in the universe that ever lived,

especially Clarice and Joseph —

my best and truest friends forever and ever and ever.

Declaration

I declare that the contents of this thesis, unless otherwise referenced, is all my own work and ideas. Any elements of this work which have been published, or are the outcome of research collaborations, are clearly stated at the beginning of the thesis chapter where the content resides. This thesis has not been submitted for the award of a higher degree anywhere other than the Lancaster University, and for any degree other than for the degree of Doctor of Philosophy.

Helena Tendedez
August 2020

Acknowledgements

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Abstract

Millions of people across the world are affected by Chronic Obstructive Pulmonary Disease (COPD). It is one of the most prevalent chronic health conditions in the world. As a life-long condition that effects breathing, it has a huge physical and mental impact on peoples' lives every single day. COPD is characterised by periods of respiratory exacerbations which, if are not managed swiftly, can result in hospitalisation for emergency care. However, effective self-management and support can help people with COPD to avoid the distress of requiring emergency care, while supporting their quality of life and independence.

In addition to the difficulties that COPD introduces to a plethora of people, it also presents a huge challenge for healthcare services around the world. In the UK, COPD generates a high number of hospital admissions annually, with many of these for emergency care. In this highly demanding and time-pressured context, healthcare professionals are required to make timely and evidence-based decisions to effectively care for patients. This is the challenging reality for all healthcare professionals that collaborate in the ongoing management and support involved for COPD care.

Data supported decision-making (DSDM) technology holds potential to support the ongoing care of people with COPD, through connecting them and their health-care professionals with pertinent data that can inform decision-making around care. Examples of such technologies include patient health monitoring apps that share data with healthcare professionals for personalised care planning, and clinical dashboards that interlink data from different sources to support decision-making about patient treatment. However, there is currently limited research working in partnership with people with COPD and respiratory healthcare professionals to truly understand how these technologies might support care in its real-world context.

Specifically, there are three key gaps in knowledge which this thesis addresses. First, there is a need to understand how DSDM technologies can be designed to support healthcare professionals to provide COPD care, while considering the chal-

lenges of implementing technology into healthcare systems. Furthering this, there is a need to understand how technology could support the self-management of COPD, considering it is progressive and highly debilitating in nature. Finally, there is a need to understand how technology could support the ongoing care collaboration between healthcare professionals and patients through sharing patient-generated data about COPD symptoms. Each of these three areas are important in developing an understanding about how technology could support the real-world context of COPD care.

To advance our knowledge in this space, I conducted three novel pieces of research working with people with COPD and healthcare professionals to understand how DSDM technologies could support everyday challenges related to COPD care. First, I worked with 11 healthcare professionals to co-design a DSDM dashboard by exploring their decision-making needs around COPD care. Then I conducted exploratory research involving 171 people with chronic respiratory conditions to understand how technology may support their self-care. Finally, I conducted a small exploratory case study with eight participants to understand the patient experience of self-monitoring their respiratory symptoms and the healthcare professionals' experience of receiving this data remotely.

The thesis concludes with a synthesis of the key novel findings across the three research studies, providing overarching opportunities and nodes of caution when designing and deploying DSDM technologies in this space. This discussion draws attention to the ways that perceptions of data 'trustworthiness' affects how DSDM technologies are used for decision-making, the tensions that occur when technology does not align with the local context of care, the need for self-management technology to support the personal and evolving condition journey of COPD, and how we may consider designing patient facing technologies to better accommodate potential reactive self-care patterns.

Foreword

In early 2020, while I was writing this thesis, a sudden outbreak of COVID-19 (a novel coronavirus) rapidly became a pandemic. It has claimed the lives of many people around the world, including healthcare professionals who have fought hard to save people. Though this thesis is being published during the pandemic, the research described here occurred before the discovery of the virus.

The current outbreak of COVID-19 has put healthcare services around the world under unprecedented strain, including the National Health Service in the United Kingdom. In addition to the strain on healthcare services, people with severe respiratory conditions are at high risk of developing serious complications if they contract COVID-19. It is a crucially important time for healthcare services to preserve their resources as much as possible to respond to the pandemic, and for people with respiratory conditions to self-isolate to avoid exposure to the virus. In turn, respiratory self-care has become increasingly important.

As I submit this work during a respiratory pandemic, this thesis may raise important, yet unanticipated, questions about its applicability to COVID-19. However, although COVID-19 is a respiratory disease, it is important to state that the findings from this thesis do not extrapolate directly to it.

Publications

Contributing Publications

The list below details the publications which contribute to the research described in this thesis.

1. **Helena Tendedez**, Roisin McNaney, Maria-Angela Ferrario, and Jon Whittle. 2018. Scoping the Design Space for Data Supported Decision-Making Tools in Respiratory Care: Needs, Barriers and Future Aspirations. In Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '18). **This paper contributes to Chapter 4, using the data, analysis and findings.**

2. **Helena Tendedez**, Maria-Angela Ferrario, Roisin McNaney, and Jon Whittle. 2019. Respiratory Self-Care: Identifying Current Challenges and Future Potentials for Digital Technology to Support People with Chronic Respiratory Conditions. In Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '19). **This paper contributes to Chapter 5, using the data, analysis and findings.**

3. **Helena Tendedez**, Maria-Angela Ferrario, and Roisin McNaney. 2019. 'The Issue With That Sort of Data...': Clinicians' Accountability Concerns Around COPD Self-Monitoring Tools. In Companion Proceedings of the 2019 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '19). ACM, Austin, Texas, USA. **This extended abstract contributes to Chapter 6, using the data, analysis and findings.**

Additional Publications

The list below details additional publications which do not contribute to the content of this thesis, but which I have written during my time as a PhD student.

1. **Helena Tendedez**, Kelly Widdicks, and Mike Hazas. 2018. Planning for the Things You Can't Plan for: Lessons Learned from Deployments in the Home. Interactions. 26, 1. 52-57. ACM, New York, NY, USA.

2. **Helena Tendedez**, Maria-Angela Ferrario, and Jon Whittle. 2018. Software Development and CSCW: Standardization and Flexibility in Large-Scale Agile Development. Proceedings of the ACM on Human-Computer Interaction. 2, CSCW, Article 171 (November 2018). ACM New York, NY, USA.

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Chapter 1

Introduction

We will all need healthcare at some point in our lives. For some people healthcare is required more often than for others. This is particularly true for people with chronic health conditions; which are long-term continuous or reoccurring health problems (Bernell and Howard, 2016). Advancements in medicine mean that the global population is now less prone to death from infection and infectious diseases, and so on average, we live longer (Suzman and Beard, 2011; World Health Organization, 2017). Yet, as we live longer, we become more likely to develop chronic health conditions like chronic respiratory conditions, cardiovascular diseases, cancers, and diabetes (World Health Organization, 2018b). Chronic health conditions are by far the leading causes of death globally (Vita-Finzi et al., 2005; World Health Organization, 2018a), resulting in tens of millions of deaths annually (Wang et al., 2016). These conditions create a considerable challenge for millions of peoples' lives and many healthcare services around the world (National Institute of Health, 2017; Snell et al., 2016a,b; World Health Organisation, 2018). For this reason, understanding how to best support the lives of people with chronic health conditions is a pressing area for research (Davis et al., 2000; Dixon, 2004).

Chronic respiratory conditions (CRCs) are among the most prominent chronic health conditions in the world (Wang et al., 2016). Chronic Obstructive Pulmonary

Disease (COPD) is one of the most common CRC. Risk factors which increase the chance of developing COPD include cigarette smoking and various environmental factors, such as smoke inhalation and air pollution (Mannino and Buist, 2007). The term COPD describes a set of chronic and progressive lung conditions. These lung conditions make it difficult to breathe, subsequently impacting everyday life for people with the conditions and their families. There are an estimated 328 million people living with COPD worldwide (Eisner et al., 2010; Quaderi and Hurst, 2018). Fortunately, the condition can be effectively managed with the right ongoing support. Quality of life can be supported through effective self-management of the condition, paired with support from family, friends, and respiratory healthcare professionals (HCPs) (DiNicola et al., 2013; Gadoury et al., 2005; Holman and Lorig, 2000; Russell et al., 2011). However, COPD still remains a considerable challenge to so many lives and healthcare services around the world (National Institute of Health, 2017; Snell et al., 2016a,b; World Health Organisation, 2018). As such, understanding how we can support the lives and care of the millions of people that have COPD is an important and worthwhile area of study.

Lung diseases, like COPD, cost the United Kingdom's (UK) National Health Service (NHS) approximately £1.9 billion each year (British Lung Foundation, 2014). In the UK, COPD generates a high number of emergency hospital admissions annually, with 97% of COPD admissions being for emergency care (Snell et al., 2016b). Unplanned hospital admissions are a distressing experience for patients and their families. They also put tremendous pressure on HCPs who are responsible for making timely, life-saving decisions each day. When caring for patients with chronic health conditions like COPD, HCPs often rely on information from a range of different sources and HCPs to make ongoing decisions about care (Casas et al., 2006; Dobler, 2016; Nolte et al., 2012; Smith, 1996). The prompt retrieval of relevant health information about patients is important to support the time-pressured HCP to make informed and effective decisions about care.

Technology has had an important role in transforming healthcare over the past century (Hatcher and Heetebry, 2004; Spekowius and Wendler, 2006; Thimbleby,

2013; Timmermann and Anderson, 2006; Wright et al., 2012), which has led to the field of 'digital health' as an area of interest for research (DePasse et al., 2014; Lupton, 2014a). The introduction of Electronic Health Records is a notable example of how technology has transformed healthcare, enabling patient data to be stored digitally and thus being potentially more accessible than paper records (Evans, 2016). Electronic Health Records enable *data supported decision-making* (DSDM), in that they provide pertinent data that can support and inform decisions about healthcare. The concept of DSDM is central to healthcare; HCPs will aim for optimal care outcomes by considering a collage of medical information and evidence (Smith, 1996). Likewise, people with chronic health conditions may collect data about their symptoms and experiences to craft effective self-care practices. Digital health technologies which provide data that supports and informs decision-making in this way can be considered *DSDM technologies*. Examples of DSDM technologies used across healthcare include clinical dashboards that visualise data to support the delivery of patient care (Dowding et al., 2015), and technologies that support people to collect data about their health through the practice of self-monitoring (Lupton, 2017). Both of these technologies present data that can help to inform care at different points and in different ways.

To that end, we can then begin to envision how DSDM technologies could be designed to provide timely and data-driven support for COPD care. This could positively impact the lives of people with the condition and the work of HCPs who care for them. However, to truly understand where potential opportunities lie in this space, it is crucial to first develop a rich understanding of the needs of those involved with COPD care. This can be achieved through actively engaging HCPs and people with COPD within computer science research, using participatory methods for technology design and development (Sanders and Stappers, 2008). By doing so we can ensure what is created is driven by real-world needs faced by those directly impacted by COPD, instead of developing pre-conceived technical solutions (Liu et al., 2006). For this reason, my research involves working *with* people with COPD and respiratory HCPs to explore the potential role of DSDM technologies to support care.

1.1 Research Context

The field of Human-Computer Interaction (HCI) takes an interdisciplinary approach to understand the interplay between people and technology (Dix, 2009). The aim of HCI research is to observe how technology influences human work and activities (Dix, 2009; Preece et al., 1994). Previous HCI research has documented the different ways in which digital technologies can support healthcare (Fitzpatrick and Ellingsen, 2013). The goals of these HCI studies are to understand how engaging with these technologies may provide support, and in some instances improvement, to healthcare and how it is delivered. This thesis aims to add to this body of HCI research in healthcare, by working directly with those impacted by COPD to explore the role that DSDM technologies may have for supporting care. It is important to note that decisions about care are not just made by HCPs in clinic settings, they are also made by people with COPD as they practice self-care in their everyday lives. As such this thesis actively seeks to explore how DSDM technologies can support the ongoing decisions about care made by *both* respiratory HCPs and people with COPD.

There is a relatively limited amount of digital health research that explores how technology can support the self-care of people with COPD. Most studies in this space focus on the creation of novel technical systems that aim to support COPD care. For example, there are numerous studies about using novel machine learning techniques to detect declines in health for people with COPD (Anastasiou et al., 2018; Chatterjee et al., 2019; Fernandez-Granero et al., 2018; Gokalp and Clarke; Hofer et al., 2015; Merone et al., 2016; Nathan et al., 2019b; Sanchez-Morillo et al., 2015). While these studies demonstrate the impressive technical capabilities of digital health technologies, there is a strong need to work with people with COPD to understand how technology can address their real needs and fit into their everyday lives.

In fact, within the limited number of studies that explore technologies for COPD self-care, even fewer studies have involved people with the condition in their research (Dahl et al., 2018; Johnston et al., 2009; Nadarajah et al., 2019; Pereira et al., 2016; Spina et al., 2013). Considering COPD is a complex chronic health condition

that introduces many mental and physical challenges into people's lives (Cicutto et al., 2004; Cicutto and Brooks, 2006), there is much to learn about their experiences and needs which will shape the support that is created. This rich perspective is generally missing from HCI research, which represents a prominent gap in current knowledge. Enhancing this knowledge is an essential research pursuit that would help to understand if, and how, technology might support the lives of people with COPD.

Technologies that aim to support HCPs' decision-making are generally better researched. Though not specific to respiratory care, there has been a wealth of previous work about clinical decision-support systems and dashboards (Dowding et al., 2015; Iftikhar et al., 2019). These technologies have been created to support reductions in hospital admissions (Alluhaidan et al., 2015), best practice adherence (McMenamin et al., 2011), identifying patients that require follow up care (Croon et al., 2015), and medication monitoring (Waitman et al., 2011). Most previous work in this space details the technical creation of these systems, or the quantitative evaluation of their clinical effectiveness. While these technologies demonstrate great potential to support decision-making, there is a lack of rich understanding about how HCPs may engage with these technologies in practice to support their work.

Moreover, previous work has shown that there is difficulty integrating digital health technologies into clinical practice. Some of the reasons for this are: poor cultural fit; failing to meet user demand; or lack of integration with other key clinical systems (Fitzpatrick and Ellingsen, 2013; Grimson et al., 2000; Liu et al., 2006). This presents a strong case for the need to involve HCPs in the design of DSDM technologies to unpack, and address, these challenges in greater detail. There is limited HCI research that details the complex cultural and technical challenges that arise when designing DSDM technologies for healthcare. A stronger understanding of this process can help to form a deeper appreciation of the challenges and opportunities in this space. This brings the field of HCI a step closer to understanding how DSDM technologies can be designed to integrate into real-world clinical practice. It is at this point where the benefits of using these technologies can truly be realised.

Given the gaps evident in previous HCI research, there is still much to learn about

the role of DSDM technologies for respiratory care. This thesis takes an interpretivist and pragmatist approach to deepen our understanding of this role. I build a body of empirical evidence about the experiences and needs of those involved in COPD care, with a view to understanding the opportunities for DSDM technologies. To do this, I conduct three pieces of novel research that engage both respiratory HCPs and people with COPD to understand the context of care. Within these studies, I carefully uncover the opportunities and challenges in this space from these key perspectives. I also outline opportunities for future work that can advance this area of research.

1.2 Research Questions and Setting

This section outlines the research questions that this thesis addresses, followed by an overview of the research setting.

1.2.1 Research Questions

This thesis aims to contribute an exploration of the potential role of DSDM technologies for respiratory care. To explore this in detail from the perspectives of HCPs and people with COPD, I have chosen to focus on three main research questions:

1. How can technology support healthcare professionals in their decision-making for COPD care?
2. What is the lived experience of COPD, and how can technology support this experience?
3. What is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals?

1.2.2 Overview of Research Setting

This research was conducted with participants from two collaborating healthcare organisations, and members of the CRC community, in North West England. The aim was to explore the potential role of DSDM technologies for COPD care, both in clinical settings and everyday life as motivated above. I briefly summarise the research setting below, providing more detail in later chapters.

To explore DSDM from the HCPs' perspective, I worked with two collaborating NHS organisations. The NHS is the UK's publicly funded national healthcare system. The two organisations operated, respectively, a hospital respiratory service and a community care service. Both organisations work together to provide respiratory care services to COPD patients in their region. The hospital respiratory service provides urgent, specialised, and emergency care services to patients. Community care provides diverse support services for that promote self-management, independence, and hospital admission avoidance through home visits. The organisations collaborate through provision of care: once a COPD patient has been discharged from the hospital service, they usually receive follow-up care from the community care service. COPD represents a high demand on their joint services, and so they were motivated to explore how DSDM technology could support their work.

Specifically, they were motivated to explore how the aggregation and presentation of pertinent data about their COPD patients and services could help inform their decision-making (Chapter 4). It was thought that this information, displayed on a joint dashboard, could help them to make timely data-supported decisions. This could improve the care offered to patients and subsequently help to reduce service demand. In addition to this, the community care service were interested to explore how technology could support and educate their COPD patients (Chapter 6). Particularly, they wanted to explore how self-monitoring technology might fit in with their service and assist patients to self-manage their condition through better awareness of their symptoms. It was thought that this could help to improve patients' quality of life, while reducing the pressure on their service.

To explore DSDM technology with people with COPD, I engaged the wider CRC community by largely working with respiratory support groups (Chapter 5). These groups, called Breathe Easy groups, are supported by a UK charity organisation called the British Lung Foundation. The groups are self-organised and run by members of the respiratory community, including friends and carers. I focused on participants' experiences of care, self-care and self-management, and technology. While my research activities with HCPs focused on specific types of technology (a dashboard and self-monitoring technology), my research with the CRC community took a more open-ended and exploratory approach about the possibilities for digital support.

Figure 1.1 provides a visual depiction of how each of my research chapters (Chapter 4, 5, and 6) contribute to my three research questions. Note that each research chapter contributes to more than one research question.

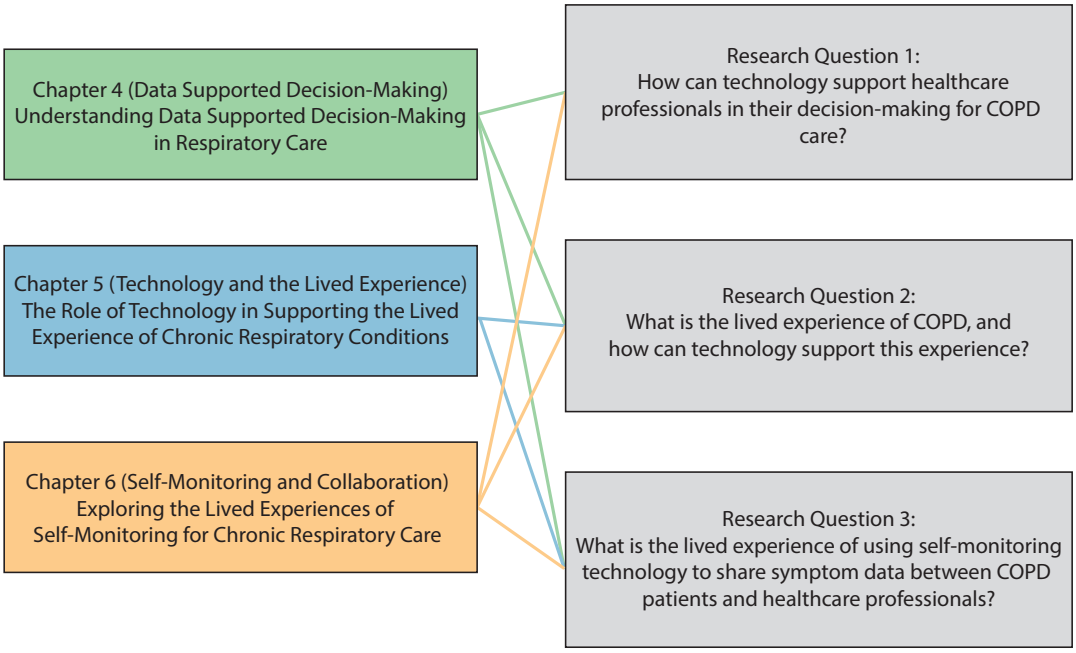

Figure 1.1: How each research chapter contributes to each research question.

1.3 Contribution Statement

Through exploring the three research questions outlined in the previous section, my thesis provides a number of contributions to the fields of HCI and Health Informatics. The primary contribution is about growing our understanding of the role that DSDM technologies could have for COPD care. I contribute this understanding from the key perspectives of both people with the condition and respiratory HCPs. More specifically, this thesis considers how DSDM technologies can be designed to take into consideration the specific needs and complexities of COPD care. However in addition to this primary contribution, I also make six further contributions:

1. I have identified prominent gaps in knowledge about DSDM technologies in healthcare, through interweaving research from HCI, computer science, health informatics, and social science literature (Chapter 2). In addition to motivating this thesis through the literature synthesis, Chapter 2 lays the foundation for future research avenues beyond this thesis.

2. I take the reader on a previously unexplored journey to understand how real-world DSDM occurs for COPD care (Chapter 4). I explore how technology could feasibly support this process. Through involving diverse stakeholders, I provide novel empirical contributions in addition to specific conceptual contributions about how trust in data impacts DSDM. I conclude with insights about how we may begin to design DSDM technologies for respiratory care that account for the real-world challenging nature of clinical practice.

3. Through my research engagements with the CRC community in Chapter 5, I have detailed a rich account of the salient challenges and experiences of living with COPD. This has allowed me to identify novel opportunities for self-care technologies to support this experience. Particularly, I contribute an understanding of where DSDM technologies may be most needed to support the COPD journey. I conclude with important recommendations, grounded in the lived experience of COPD, for those designing self-care technologies in this space.

4. From the viewpoints of both patients and HCPs, Chapter 6 provides real-world insights into the COPD self-monitoring process and remote sharing of this data. This case study provides a recognition of the values placed in the self-monitoring and data sharing process. It also explores the concerns and challenges involved with recording and remotely sharing personal health data about COPD, including the conceptual challenge of accountability. I conclude by identifying opportunities and nodes of caution for designers of COPD self-monitoring technologies.
5. I synthesise my key contributions in Chapter 7 (Discussion), drawing on the findings from each research chapter (4, 5, and 6). I clearly outline my overall contributions to knowledge, situating them within previous work in this space. Overall, this shows how this thesis has advanced understanding about the potential role of DSDM technologies for respiratory care.
6. When concluding this thesis in Chapter 8, I outline opportunities for future work to directly build on this thesis. This contributes a clear understanding of the next steps that are required to further knowledge in this space.

1.4 Thesis Structure

This thesis is structured into eight chapters, which sequentially take the reader through the journey of this PhD research. The structure of this thesis is discussed below, with a summary of the contents of each chapter.

To gain a deeper understanding of COPD, **Chapter 2** (Background and Related Work) begins by introducing COPD in more detail by describing its prevalence, causes, diagnosis, and the importance of self-management and self-care. This prepares the reader with enough foundation knowledge about the condition to appreciate the challenges raised throughout the thesis. It also explains the overlap between COPD and CRCs more generally, justifying my inclusion of the CRC community more widely in this research. Following on from this, I critically examine the current literature

around DSDM in healthcare, the challenges when innovating in the healthcare space, technologies for COPD self-management, and sharing personal health data about COPD. This chapter draws on literature from various relevant disciplines, including medical sciences, computer science, HCI, and social sciences. It identifies prominent gaps in this space, which motivates my three research questions.

Following on from the critical examination of the literature and the identification of knowledge gaps, **Chapter 3** (Methodology) discusses the methodological approach for this thesis. I begin by introducing and justifying my mixed methods approach, which includes a discussion of my chosen frameworks. Then I introduce my specific research methods, approach to data analysis, the healthcare setting for this research, and participant recruitment. I conclude by discussing the various important practical, ethical, and methodological considerations which shaped this research.

My first research study is **Chapter 4** (Understanding Data Supported Decision-Making in Respiratory Care). It explores DSDM in respiratory care from the experiences of HCPs. This chapter documents the design and evaluation of a DSDM prototype that aims to support decision-making about COPD care and services. Through uncovering HCPs' data needs that could be supported by technology, this study also uncovers the real-world challenges and complexities of designing DSDM technologies for healthcare. This chapter contributes a rich understanding about the experiences, opportunities, and limitations of DSDM in respiratory care — directly demonstrating how this impacts how these technologies should be designed and deployed.

To truly understand how technology might support people with CRCs, **Chapter 5** (The Role of Technology in Supporting the Lived Experience of Chronic Respiratory Conditions) details a series of research engagements with the CRC community to understand their lived experiences. This chapter provides a rich understanding of people's experiences living with CRCs, how they self-manage and self-care, and how technology could support these practices. It identifies opportunities for technology to support the needs of people with CRCs, followed by challenges which arise in this design space that require careful consideration.

To unite HCPs and COPD patients together as part of ongoing care, **Chapter 6** (Exploring the Lived Experiences of Self-Monitoring for Chronic Respiratory Care) explores the experiences of self-monitoring COPD symptoms and sharing the resulting data with HCPs. This chapter took an exploratory case study approach. It involved patients self-monitoring their COPD symptoms using a mobile health app, which remotely sends the data to their HCPs. It reports on the experiences and perspectives of both patients and HCPs during the case study. I conclude by providing an understanding of the needs that patients and HCPs have in relation to the self-monitoring process, and the challenges that arise when sharing data remotely in this way.

Synthesising the overall contributions of the thesis, **Chapter 7** (Discussion) revisits my research questions and discusses the contributions from all three research chapters. It incorporates key literature in the discussion to show how this thesis has advanced understanding of this space. This chapter aims to demonstrate how each research study has contributed to the overall story about 'The Role of Data Supported Decision-Making in Respiratory Care'. It concludes by briefly summarising how my thesis can be positioned among previous research in this space.

Finally, **Chapter 8** concludes the thesis, presenting clear opportunities for future work which expand on my research. The chapter ends with my concluding remarks about this research as a whole.

1.5 Chapter Summary

This chapter has inaugurated the thesis by motivating its importance and relevance in today's world and potential future worlds. I have explored the concept of DSDM in healthcare through the lens of HCI, laying the foundation for its focus within the remainder of the thesis. Then, I outlined the three research questions which shape this thesis and introduced the research setting. Following this I provided summary statements on my contributions to knowledge. This chapter concluded with a clear outline of the thesis structure, explaining the purpose of each chapter.

Chapter 2

Background and Related Work

This chapter is divided into four main topics which provide an understanding of the background and related work on data supported decision-making (DSDM) and Chronic Obstructive Pulmonary Disease (COPD) (self-)care. Within the review of related work, I identify the areas in which this thesis aims to contribute. The first topic of this chapter explains the prevalence, cause(s), symptoms, diagnosis, and ongoing management of COPD. This exploration is important for understanding the context and unique challenges that are involved with COPD care as encountered in the research chapters. The second topic of this chapter explores the concept of DSDM in healthcare and the challenges when innovating in this space, reviewing previous work spanning Human-Computer Interaction (HCI), Computer-Supported Cooperative Work (CSCW), and Health Informatics. The third topic presents a review of previous digital health literature about COPD self-management technologies. The final topic then discusses literature on self-monitoring technologies for COPD and experiences surrounding their use, followed by how personal health data can be used by healthcare professionals (HCPs) to inform care.

2.1 Understanding Chronic Obstructive Pulmonary Disease

COPD is one of the most common chronic respiratory conditions[1] in the world (World Health Organisation, 2018). There are an estimated 16 million people living with COPD in the United States (US) and 1.2 million in the United Kingdom (UK) (National Institute of Health, 2017; Snell et al., 2016b). In the UK, COPD generates over 140,000 hospital admissions annually, accounting for over one million bed days[2] — with 97% of these admissions being for emergency care (Price et al., 2006; Snell et al., 2016a). COPD is characterised by non-reversible chronic obstruction of the airways which results in breathlessness (Elkington et al., 2004; Miravitlles et al., 2006; Wedzicha and Seemungal, 2007). COPD describes conditions such as emphysema and chronic bronchitis (Madison and Irwin, 1998; Petty, 2006).

Emphysema and chronic bronchitis are chronic respiratory conditions which make breathing challenging for different biological reasons. Emphysema is a lung disease which progressively destroys the alveoli (the tiny air sacs) of the lungs (British Lung Foundation, 2016; Thurlbeck, 1984). It causes the inner walls of the single alveoli to rupture, ultimately creating larger air sacs which reduces the surface area of the lungs (National Emphysema Foundation, 2005; Thurlbeck, 1984). This leads to a decrease in the amount of gases exchanged in the lungs, making breathing difficult. Chronic bronchitis is caused by the overproduction of mucus, which causes airflow obstruction and difficulty breathing (Kim and Criner, 2013). It is not the same as acute bronchitis, which is usually temporary and caused by a viral infection.

[1] Chronic health conditions are long-term continuous or reoccurring health problems (Bernell and Howard, 2016).

[2] Bed days refer to the number of days that a hospital bed has been allocated to a patient with a particular condition. If COPD accounts for over one million bed days a year, that means that COPD patients spent over one million combined days a year occupying hospital beds.

Research suggests that nearly all patients with COPD experience the effects of both emphysema and chronic bronchitis (Niewoehner, 2012). The terminology associated with COPD has been raised as challenging for patients to understand, with some patients expressing a lack of knowledge about what COPD means (Powell et al., 2013). Adding to this, it is possible to have more than one respiratory condition simultaneously (Miravitlles et al., 2012). For example, having both asthma and COPD, referred to as Asthma COPD Overlap Syndrome (Barnes, 2016; Barrecheguren et al., 2020; Bujarski et al., 2015). Asthma is also a common chronic respiratory condition, causing the lining of the airways to become inflamed and narrowed (Hargreave and Nair, 2009). Asthma COPD Overlap Syndrome describes instances where a patient has clinical features of both COPD and asthma simultaneously. It is important to note that COPD and asthma differ in the nature of their inflammation, and as a result, require different respiratory medication (Murphy, 2019). However, characteristics of COPD and asthma can be similar, leading to misdiagnosis in practice due to uncertainty (i.e. people with COPD being diagnosed as having asthma and vice-versa) (Arne et al., 2007; Bellia et al., 2003; Buist, 2003; Fletcher and Pride, 1984; Murphy, 2019; Tinkelman et al., 2006).

The main cause of COPD is cigarette smoking, although second-hand smoke inhalation, air pollution, breathing noxious materials, and having an alpha-1-antitrypsin[3] deficiency are also causes of COPD (British Lung Foundation, 2016; Goldklang et al., 2013; Hu et al., 2010; Mannino and Buist, 2007; National Heart, Lung, and Blood Institute, 2019; Viegi et al., 2001). People that develop COPD usually begin to experience symptoms after the age of 40 or 50 (Jarad, 2011; Marcus et al., 2015; Shavelle et al., 2009; World Health Organisation, 2016) or when their condition has advanced (Gulsvik, 2001), but people can develop COPD at any age (Morice et al., 2010). People with COPD will experience breathlessness, frequent chest infections,

[3]Alpha-1-antitrypsin is a protective enzyme inhibitor produced by your liver. When you have a deficiency of alpha-1-antitrypsin, you are more vulnerable when inhaling certain substances like cigarette smoke.

wheezing, and fatigue. These symptoms may be experienced on a regular basis or exacerbated by specific triggers. Triggers make it difficult for individuals to engage in everyday life such as leaving their home, socialising, and dressing or washing oneself. Triggers can include respiratory viral infections, common colds, physical exertion, smoke inhalation, and environmental factors such as high pollen counts and air pollution (British Lung Foundation, 2018; Hu et al., 2010; Johnston et al., 2017; McManus et al., 2008; Sama et al., 2017).

Triggers can cause an 'exacerbation' of the condition. An exacerbation is a health event that is characterised by a change in a person's baseline breathlessness, cough, or sputum (phlegm) that is considered unusual for that person (i.e. outside of their normal day to day symptom variations) (Hurst and Wedzicha, 2007). An exacerbation is usually acute in nature and may warrant a change in the person's medication (Calverley et al., 2003; Hurst and Wedzicha, 2007). For example, they may be prescribed antibiotics or steroids to manage the exacerbation or require a change in their daily medication. Exacerbations can be infective (caused by bacterial infection and treated with antibiotics) or non-infective (caused by factors such as the environment and comorbidities, which are not treated with antibiotics) (Ko et al., 2016; National Institute for Health and Care Excellence, 2019; Qureshi et al., 2014; Sapey and Stockley, 2006).

The symptoms of COPD can place restrictions on people's lives. For example, physical and social restrictions introduced by the condition can cause people to feel depressed and anxious (Cicutto et al., 2004; Clari et al., 2017; Maurer et al., 2008; Stage et al., 2006; van Manen et al., 2002; Yohannes and Alexopoulos, 2014). Similarly, feelings of constant breathlessness can cause people to feel fearful of being alone in case exacerbations occur (Powell et al., 2013). As such, the condition journey is one that can involve severe social and emotional challenges.

2.1.1 Diagnosis

The three main criteria to consider when deciding whether to test a patient for COPD are outlined by National Institute for Health and Care Excellence (2010a) as follows: (1) the patient is a smoker or has been in the past; (2) the patient is over 35 years of age; and (3) the patient presents with at least one of the following symptoms: exertional breathlessness, chronic cough, regular sputum production, frequent winter bronchitis, and wheeze. The diagnosis of COPD usually occurs by the patient taking a spirometry test (Derom et al., 2008). This is achieved by the patient performing three forced blows into a spirometer device, which is a medical device that measures lung function. It does so by calculating the volume, flow, and speed of air that is exhaled by the patient (Moore, 2012). The results of the test can indicate if the patient's airways are obstructed. As part of the diagnosis process, the HCP may also order a chest radiograph (a technique that uses X-rays to create an image of an internal structure), a full blood count (measuring the number and types of cells that are in a person's blood (NHS, 2016)), and calculate the patient's body mass index (which calculates if a person's weight is healthy in relation to their height) (National Institute for Health and Care Excellence, 2010a). If there is diagnostic uncertainty, the HCP may refer the patient to see a respiratory specialist for clarification (Conway et al., 2015). This referral is also made if the patient is found to be very severe and needs specialist input (Conway et al., 2015).

If a diagnosis of COPD is confirmed then the patient will be prescribed medication to help manage their symptoms and daily life. The prescribed medication will depend on the patient's needs, but usually includes steroid inhalers which are used to prevent symptoms and bronchodilator inhalers ('rescue inhalers') which are used to manage flare ups (British Lung Foundation, 2019). To assist the intake of medication, patients may use a spacer or a nebuliser. Spacers are plastic containers which sit between the inhaler and the patient's mouth, by spraying the inhaler into the spacer the medication can be inhaled at an easier pace. A nebuliser is a device which administers the inhaler medication in the form of a mist, connected to the patient's mouth

through a mask, which makes it easier to inhale. In more severe cases, patients may be prescribed oxygen to use at home for a certain number of hours each day to assist with breathing (Rous, 2008). A 'rescue pack' may also be given to patients, which contains emergency antibiotics and steroid tablets to take at the onset of an exacerbation (Schomberg et al., 2011). It is thought that by issuing rescue packs, patients can treat themselves at home in a timely way to avoid hospital admissions (Schomberg et al., 2011).

The timely treatment of exacerbations is important, as delaying treatment can lead to worse health outcomes for patients (Wilkinson et al., 2004). However, prescribing a rescue pack is at the discretion of the HCP. For example, some HCPs are concerned whether patients are educated enough about when they should use their rescue pack, with some HCPs holding the belief that antibiotics should only be taken under their explicit instruction (Davies et al., 2014; Robinson, 2018). Whereas other HCPs have discussed that rescue packs can help patients to quickly manage their condition on their own without needing to wait for an appointment to see a doctor during an exacerbation (Davies et al., 2014).

Previous work has noted how patients with COPD generally have a low adherence to their prescribed medication by underusing it (Arnold et al., 2011; Rand, 2005; Restrepo et al., 2008). Studies that track medication adherence have shown that some patients 'dump' their medication to appear to HCPs that they are adhering (Dolce et al., 1991). Non-adherence to medication is thought to be influenced by numerous factors including patients' understanding of their condition, disagreement with physicians' prescribing choices, and lack of confidence in prescribed medication with a preference for natural remedies to treat symptoms (Antonelli et al., 2001; Dowson et al., 2004b; George et al., 2005; Restrepo et al., 2008; Turner et al., 1995).

After a confirmed diagnosis of COPD, patients will receive information about how to manage their condition by their HCP. This information will centre mostly on how to avoid exacerbations, which can lead to emergency hospital admissions and worsening of the condition (Rennard and Farmer, 2004; Wedzicha et al., 2014).

2.1.2 Ongoing Management

Following diagnosis, patients will be encouraged to effectively self-manage their condition at home as part of everyday life. As COPD is a progressive chronic condition, it requires ongoing management from the patient themselves, carers, and HCPs. Self-management and self-care can help improve the quality of life for the patient, and potentially save healthcare costs significantly (Bourbeau et al., 2006; Cannon et al., 2016; Department of Health, 2011; Zwerink et al., 2014). 'Self-management' focuses on managing a specific health condition, defined as an 'individual's ability to manage the symptoms, treatments, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition' (Barlow et al., 2002). 'Self-care' takes a more holistic approach that considers the person's life beyond their health condition, being defined as 'activities performed by individuals or communities to achieve, maintain, or promote maximum health' (Richard and Shea, 2011). Effective self-management and self-care is an important part of living with COPD. Education about self-management can help individuals to improve their quality of life, physical function, and avoid hospitalisation (Gadoury et al., 2005; Yu et al., 2014).

Carers, such as family members and friends, can support daily life for people with COPD by providing emotional and physical support (Gardiner et al., 2010; Seamark et al., 2004). For self-management, people with COPD will carry out actions and activities such as avoiding triggers, taking medication as prescribed, smoking cessation (if the patient is a current smoker), annual influenza vaccinations, using their inhaler correctly, and daily exercise (AL-Jahdali et al., 2013; Bekkat-Berkani et al., 2017; Cicutto and Brooks, 2006; Effing et al., 2011, 2012; Pesek and Lockey, 2011; Pothirat et al., 2015; Tønnesen, 2013). However, there are more subtle and unique challenges that individuals with COPD will have to address as part of the ongoing experience of their condition. For example, learning to adjust to the physical limitations that COPD introduces, and dealing with perceptions of 'dying' that impact emotional health (Cicutto et al., 2004; Giacomini et al., 2012; Seamark et al., 2004). These challenges extend beyond what can be learnt from the HCP, and instead are learnt

through the unique lived experience of the condition.

In some instances people may be advised to keep track of their symptoms to support their self-management. For example, by taking regular readings on a peak flow meter (a mechanical device that measures expiration speed) or keeping a diary of their symptoms to discuss during periodic reviews with HCPs (In 't Veen et al., 2014; Kulich et al., 2015; van Kruijssen et al., 2015; Walters et al., 2012; Worth, 1997). During annual reviews with their General Practitioner (GP) or practice nurse, patients will usually undertake a spirometry test to compare and monitor lung function over time. If the patient is having difficulties managing their condition, they may be referred to healthcare services or professionals that can help; for example: smoking cessation services (services that help patients to stop smoking); pulmonary rehabilitation classes (exercise and education classes aimed at supporting patients with respiratory conditions); or an appointment with a respiratory specialist. The HCP may ask the patient to rate their breathlessness using the Medical Research Council Dyspnoea Scale during these appointments, to understand the patient's perceived respiratory disability in daily life. The Medical Research Council Dyspnoea Scale is a scale from one (representing 'not troubled by breathlessness except on strenuous exercise') to five (representing 'too breathless to leave the house, or breathless when dressing or undressing') (Bestall et al., 1999; Paladini et al., 2010; Stenton, 2008). This rating may be used to complement the annual spirometry result, and may be compared each year or after certain interventions (Elkhateeb et al., 2015).

Between annual reviews, if the patient becomes unwell or exacerbates, they may make an appointment to be reviewed by their GP. In emergency situations, such as when the patient is experiencing a severe exacerbation, this process may be bypassed altogether and the patient will be admitted to hospital for emergency care.

2.1.3 Summarising Understanding

This section provided an overview of COPD. I discussed its prevalence, symptoms and causes, the complexities surrounding diagnosis and medication adherence, and the activities carried out, and challenges experienced, as part of the condition journey. The following sections review the literature around DSDM in healthcare and the challenges innovating in the healthcare space, technologies for COPD self-management, and self-monitoring technologies for COPD and the experiences of their use. Within the literature review, I identify the relevant gaps in knowledge where my thesis aims to contribute through my research questions.

2.2 Data Supported Decision-Making in Healthcare

Many academic disciplines are interested in the process of how decisions are made, including psychology, philosophy, economics, and computer science (Beach and Connolly, 2005; Boos and Jacquemart, 2000; Bruch and Feinberg, 2017; Herbert, 2000; L. Martin, 2003; Roberts, 2008; Szaniawski, 1980; Turpin and Marais, 2004). Decision-making describes the cognitive process of considering a set of actions in a particular context, and choosing the action that will align best with the decision-maker's goals and values (Beach and Connolly, 2005; Mill and Bentham, 1987; Szaniawski, 1980). Specific to healthcare, clinical decision-making is a complex process that involves utilising an ensemble of medical knowledge and evidence to make decisions about a patient's care (Smith et al., 2008). This involves weighing outcomes and probabilities, while equally trying to assess and balance risks (Hajjaj et al., 2010).

Evidence based medicine is an example of an approach taken for clinical decision-making whereby the clinician uses their empirical experience, paired with evidence from clinical research, to optimise their decisions about patient care (Rosenberg and Donald, 1995; Sackett, 1997). Patients are also actively involved in making decisions about their own health in their everyday lives, such as when to seek professional

help, adhering to agreed treatment, and how to adapt their lifestyle to living with their condition (Broadstock and Michie, 2000; Stacey et al., 2008). 'Patient empowerment' is a core topic among medical literature, encouraging patients to think critically about their health and make autonomous informed decisions that improve self-efficacy (Anderson and Funnell, 2010). In addition to the ways that clinicians and patients make different types of decisions about care, shared decision-making is becoming an increasingly common concept to promote patient-centered care (Barry and Edgman-Levitan, 2012). Shared decision-making is the process whereby clinicians and patients collaborate during decision-making to aim for outcomes that align with the patient's informed preferences (Elwyn et al., 2010, 2012).

In this thesis, I use the term DSDM to refer to the use of pertinent data that can support and inform decision-making about healthcare. The use of the term 'data' here is broad, encompassing any form of data that is pertinent to healthcare decisions. This is not necessarily limited to digital data, it may include data such as handwritten notes made by a patient about their symptoms, which can then be used to inform their care. Using this definition of DSDM, numerous digital health technologies can be considered DSDM technologies.

For patients, DSDM technologies can be self-management technologies that generate data which assists the everyday decisions they make about their health (Nunes and Fitzpatrick, 2015; Nunes et al., 2015). For example, self-monitoring technologies that provide data support by allowing people to track their health for self-reflection, to support behaviour change or health goals, and for sharing with others as part of their care (McBain et al., 2015; Nunes et al., 2015; Schroeder et al., 2019). Nunes et al. (2015) conducted a detailed review of the different types of technologies that exist for self-care of chronic conditions, many of which provide DSDM capabilities. For example, medical devices that provide health readings and apps that use self-tracking data to provide suggestions about care activities are both types of DSDM (Nunes et al., 2015).

Numerous digital health technologies provide DSDM support to clinicians, such as Electronic Health Records, clinical dashboards, clinical decision support systems,

and computer aided detection systems. Clinicians can also use data generated by patients to aid the decision-making process (Demiris et al., 2019), such as data about their symptoms. Clinical decision support systems are a prominent example of how technology has been explicitly designed to assist clinical decision-making in practice (Alter, 1977; Berner and La Lande, 2007). Clinical decision support systems are defined as 'any computer system that is designed to help a healthcare professional make a clinical decision' (Shortliffe, 1987). These support systems can be active or passive systems (Shortliffe, 1987). Active decision support systems explicitly suggest courses of action for clinicians to undertake (Jimison et al., 2007; Lee et al., 2018), which are less common due to growing concerns about technology driving the decision-making process (Jimison et al., 2007; Miller, 1990). Whereas passive systems offer advice to a clinician only when explicitly sought (Shortliffe, 1987).

An example of a passive clinical decision support system was shown in Cai et al.'s (2019) study on designing a deep learning system to assist pathologists. The system helped pathologists to query medical images for possible cancer. In their study, a pathologist could query the system with a specific medical image and view previous cases of similar images and their respective diagnoses. Using this information, they can compare the image at hand with previous images — before making a decision about diagnosis. Similarly, computer aided detection systems are also being used to support clinicians with the visual detection of tumours (Litjens et al., 2014; Sampat et al., 2005; Tang et al., 2009). These systems typically work by using machine learning techniques to identify potential abnormalities in imaging scans of the human body, after having been previously trained on a vast number of medical images (Tang et al., 2009). Computer aided detection systems enable DSDM by assisting clinicians in the tumour identification process, by presenting its findings to the clinician who can then further assess the area called into question.

As shown, DSDM technologies feature strongly as part of digital health research to support patients and clinicians in making decisions about care. This thesis focuses on DSDM technologies, specifically understanding their potential role for providing support for respiratory care.

2.3 Clinical Dashboards for Data Supported Decision-Making

Dashboards are another form of DSDM technology, which are widely used across the healthcare domain (Dowding et al., 2015; Iftikhar et al., 2019). Dashboards are visualisation displays, which in the context of healthcare, aggregate health data in particular ways to produce insights for users. In literature reviews on dashboards used to support patient care and decision-making, Dowding et al. (2015) and Iftikhar et al. (2019) have shown that dashboards have been used to provide DSDM support for a variety of activities and stakeholders. For example, dashboards have featured in the healthcare domain for service planning around health insurance costs (Reese et al., 2013); optimising service administration by reminding healthcare services to follow up with patients (Croon et al., 2015); business intelligence uses for hospital logistics and resources (Mahendrawathi et al., 2010); tracking in-patients on mental health wards (Daley et al., 2013); performance and benchmarking for acute respiratory infections (Linder et al., 2010); identifying and alerting HCPs about potentially high risk medication combinations for patients (Waitman et al., 2011); and sharing patient reported outcome data with HCPs (Hartzler et al., 2016; Iott et al., 2019). As shown, dashboards are a common tool used to enable DSDM for healthcare delivery.

Previous work has shown how DSDM dashboards have led to positive outcomes in clinical practice and can be used to manage a range of medical conditions. For example, McMenamin et al. (2011) described a dashboard that is linked to electronic medical records, which provided reminders about health screening targets agreed between patients and clinicians. The screening targets related to smoking, alcohol consumption, and breast cancer screening. They reported a higher recording of screening tests about smoking status and alcohol consumption through its use. Whereas Waitman et al. (2011) created an adverse drug event dashboard combining data from multiple clinical systems to identify possible high-risk medication prescribing scenarios. They reported that the dashboard successfully intercepted possible high-risk scenarios. Finally, Daley et al. (2013) created a dashboard to track in-patients on mental health

wards. The dashboard tracked features such as length of stay, readmissions, and available beds. When evaluating the dashboard, they found HCPs felt they had better access to required information, improved awareness, and improved communication. These studies serve as examples of how DSDM technologies hold potential to facilitate improvement in patient care and support the work of HCPs.

However, most research on DSDM dashboards have focused on evaluating the *clinical effectiveness* or *clinical outcomes* achieved using the technology[4] (Daley et al., 2013; Dolan et al., 2013; Dowding et al., 2015; Faiola et al., 2015; Iftikhar et al., 2019; Linder et al., 2010; Waitman et al., 2011). Though this type of evaluation is important for understanding the effectiveness of the technology, there is a lack of rich qualitative insight *from users* about the technology during these evaluations. That is, these studies do not contribute an understanding of what makes these technologies effective (or not) from a qualitative, user-centered perspective (Kaplan, 2001a,b; Kaplan and Maxwell, 2005). Moreover there is a lack of understanding about how these effective DSDM technologies have been designed in the first place. This understanding can reveal important procedural, cultural, and technical challenges (or sociotechnical challenges[5]) that arise behind the scenes when creating DSDM technologies for clinical practice. Uncovering these insights can inform how we approach the design of these technologies, which is important to support their integration in real-world complex healthcare settings. I plan to widen our understanding of this area when answering my first research question: 'how can technology support healthcare professionals in their decision-making for COPD care?'

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[4]See Dowding et al.'s (2015) comprehensive review on the evaluation outcomes of dashboards that are designed to improve patient care.

[5]Ackerman et al. (2017) describes sociotechnical considerations for healthcare as those which 'investigate the analysis, design, implementation, and adaptation of systems that incorporate both the technical and the social'.

2.4 Exploring the Challenges of Designing Technology for Healthcare

Designing DSDM technologies for healthcare is a challenging task due to the complex nature of how clinical work is carried out. There are notable challenges with collecting and accessing data within the healthcare domain, which makes designing DSDM technologies particularly complex. For instance, clinical data can be incomplete and recorded inconsistently (Axelrod et al., 2011; Rowlands and Callen, 2013). An example of this is coded[6] data. Typical issues with coded data are the use of multiple codes to demarcate the same condition, or coding too generally (for example that a doctor chatted with a patient instead of coding for the actual condition) (Axelrod et al., 2011; Campbell et al., 2001; de Lusignan, 2005; O'Malley et al., 2005; Santos et al., 2008; Sunderland, 1985). This makes extracting data for analysis in new systems challenging, as it can be difficult to rely on this data to correctly identify patients being treated for a certain condition.

Another prominent challenge when designing technology for healthcare is that healthcare services may still use a combination of paper and handwritten notes to record data (Fitzpatrick and Ellingsen, 2013). The benefits of paper notes include their communicative flexibility, portability, and availability to clinicians (Fitzpatrick and Ellingsen, 2013; Heath and Luff, 1996; Luff and Heath, 1998). However, handwritten notes are difficult to analyse due to their unstructured nature, illegibility of handwriting, and the cost of anonymising data in free-text format (Axelrod et al., 2011; Collard and Royal, 2015; Long, 2003; Xu et al., 2007). As paper notes exist outside of digital systems, it can be challenging both practically and financially to integrate this large volume of information onto DSDM technologies. This potentially excludes key data

[6]Coded data is produced by a coding professional or a HCP, who will assign a code relating to the assumed condition as described in the patient's clinical documentation. These codes are then used to describe a patient's health event and for insurance purposes (Clayton and van Mulligen, 1996).

from being collated within systems, ultimately impacting the type and quality of support that is offered.

Additionally, sharing patient information between HCPs and between healthcare organisations can be particularly difficult. Interoperability[7] challenges between clinical systems remains a key issue that can limit HCPs from sharing and accessing data they require to effectively treat a patient (Atasoy et al., 2019; Azarm-Daigle et al., 2015; Benham-Hutchins, 2009; Brailer, 2005; Chong et al., 2013; Everson and Adler-Milstein, 2018; Fisher et al.; Fitzpatrick and Ellingsen, 2013; Holen-Rabbersvik et al., 2018; Holmgren AJ, 2017; Musen et al., 2014; Olaronke et al., 2013). Adding to this, the increasing digitisation of healthcare information within different clinical systems, which lack interoperability, introduces significant 'data work'[8] for healthcare staff (Bossen et al., 2019). This requires the active reorganising of work practices to support the creation and use of healthcare information — which is exacerbated by data intensive clinical systems (e.g. electronic health records) (Bossen, 2020; Bossen et al., 2019; Møller et al., 2020; Piras, 2011). This demonstrates how the introduction of new technology into clinical practice can have unintended negative consequences for healthcare staff.

Previous research has documented the dissatisfaction that HCPs have when engaging with existing clinical systems, such as systems being hard to use and being poorly developed (Weimar, 2009); difficulty searching for key information within patient records and notes (Christensen and Grimsmo, 2008); and not supporting clinical tasks effectively (i.e. treating medical work as a straighforward, linear process) (Benham-Hutchins, 2009). These areas of dissatisfaction stem from how these technologies are designed. In some cases, these pain points can lead to HCPs creat-

[7] Interoperability is related to the ability of distributed systems to work together (Gortzis, 2010).

[8] Bossen et al. (2019) defines data work as 'any human activity related to creating, collecting, managing, curating, analysing, interpreting, and communicating data'.

ing workarounds to achieve the work which the system hinders, leading to the data within the clinical systems being inaccurate or flawed (Beerepoot and Van de Weerd, 2018; Hartswood et al., 2003a; Pine and Mazmanian, 2014). On a similar note, the complexity of organisational work in clinic settings means that records may appear inaccurate and require contextual interpretation to make sense of the data (Clarke et al., 2006). Though this is not the result of a workaround, it further highlights important challenges for DSDM technologies which aggregate and visualise this data.

The challenges with data quality, format, access, and accuracy are all examples of the complexities involved when designing technology for healthcare. Moreover, the introduction of new clinical systems can cause significant additional work for healthcare staff. This has direct implications for how DSDM technologies are designed and deployed from a sociotechnical perspective. As such, it is crucial to take these challenges into account when designing DSDM technologies for healthcare. This can be achieved through taking a user-centered design approach to understand the needs of HCPs and their work environment. Indeed, a small number of studies have documented the process of working in partnership with HCPs to design DSDM dashboards which consider their needs (Bardram and Nørskov, 2008; Hartzler et al., 2016; Iott et al., 2019; Sarcevic et al., 2018; Swartz et al., 2014). However, fewer studies appear to have examined the complexities of the clinical context which the DSDM tool is being designed to support (Bardram and Nørskov, 2008; Sarcevic et al., 2018). These insights and experiences are important to document and share across the HCI community to inform how we approach the design and real-world deployment of DSDM technologies for healthcare.

Bardram and Nørskov (2008) involved a team of HCPs and hospital managers when designing a context-aware dashboard for patient safety in operating theatres. They worked with HCPs to understand their daily challenges and data needs, before creating initial designs and iteratively evaluating them in-situ together. From this collaborative process and the in-situ evaluation, they were able to revise the design of the dashboard to take into account the complexities and real-world environment of operating theatre work. For example, excluding audio warnings from the system (as

trauma patients may be awake); requiring limited user feedback (as not to be obtrusive and impair the team's focus); supporting the immediate correction of high-risk errors (as to keep up with the fast-paced environment); and the use of a large display (which limited the need for user interaction and supported easy viewing of information).

Sarcevic et al. (2012, 2018) also actively involved HCPs during the design of a dashboard that combines and displays emerging information about patients in trauma resuscitation. The aim of the DSDM dashboard was to support timely information access and promote team awareness. During the collaborative design process, they defined data needs and how paper-based information should be captured and visualised. However, they also placed a strong emphasis on understanding the wider context of how trauma resuscitation work is carried out. To do this they conducted observations, followed by simulations of the system in the trauma room to evaluate their designs. From this, they developed a stronger understanding about how decision-making is achieved in fast-paced trauma settings. This was reflected in their adapted system design, for example: avoiding the use of an additional interface for data entry (which would be too time-consuming and distracting for the team); supporting dynamic information visualisation (as the trauma team learn more information about the patient's situation); and working with HCPs to understand the *most* required information for visualisation rather than including all the data needs (as this could cause information overload during resuscitation).

The studies by Bardram and Nørskov (2008) and Sarcevic et al. (2012, 2018) are important examples which highlight the value obtained by examining the wider work practices and environments that DSDM technologies are designed for. This involves taking into account the challenges using and responding to data during decision-making, which include the data quality, format, access, and accuracy concerns discussed earlier. Working in partnership with healthcare staff can help to explore these factors in more detail and understand their subsequent implications for DSDM technology design and use. However as it stands, limited HCI work has examined the multifaceted complexities specific to the design of DSDM technologies for healthcare. Studies have noted the complexities of designing technology for healthcare settings

more generally (Ackerman et al., 2017; Thieme et al., 2016). For example, Thieme et al. (2016) discussed the difficulties of integrating research into hospital services and the cultural changes needed to introduce research projects onto hospital wards. They stressed the need for healthcare staff to be appropriately trained to effectively engage with new technology interventions.

Ackerman et al. (2017) emphasised the importance of taking a sociotechnical approach when designing healthcare technologies to ensure they are suitable for real-world contexts. They highlighted four important considerations for effective healthcare technology design. The first consideration advocates that designers and researchers dedicate time to understand the meaning, value, and logic behind healthcare practices. The second consideration focuses on understanding the social relationships, interactions, and processes that occur between patients and HCPs, to understand how technology may make these processes more effective. The third involves the identification of the multiple real-world stakeholders involved in healthcare work (HCPs, patients, family, carers, volunteers), and how their different perspectives can be considered in the design process. The forth and final consideration is about the importance of taking a participatory design approach to ensure the clear identification of stakeholder needs, experiences, and barriers.

As shown, the work by Thieme et al. (2016) and Ackerman et al. (2017) provide valuable lessons for navigating the challenges involved when designing technology for clinical practice. However, there is a requirement to further understand the challenges when designing DSDM technologies specifically. With the wealth of growing research on DSDM technologies in healthcare, this insight is increasingly needed to advance our understanding of how to effectively design and develop these technologies (Liu et al., 2006; Smith, 1996). This thesis aims to contribute this insight by working in partnership with healthcare staff to understand how DSDM technology can feasibly support COPD care. This will be explored while answering my first research question: 'how can technology support healthcare professionals in their decision-making for COPD care?'

2.5 Technologies for COPD Self-Management in Digital Health Literature

While the previous sections focused on DSDM in clinical settings, this section focuses on technologies that support self-management and self-care of people with COPD. There is an abundance of HCI research about how technology can be used to support self-management and self-care for a variety of chronic health conditions (Fitzpatrick and Ellingsen, 2013; Nunes et al., 2015). Effective self-management is a crucial part of chronic condition care (Grady and Gough, 2014), and the rise in personal device ownership presents numerous opportunities for technology to support healthcare delivery and management (Klasnja and Pratt, 2014; Ofcom, UK, 2013; World Health Organization, 2011b).

Nunes et al.'s (2015) review of 29 HCI papers about self-care demonstrated how digital health technologies have been designed for a range of chronic conditions. They reviewed many technologies designed to support reflection on symptoms; suggest and share information about self-care activities; promote collaboration between patients and their care network; and provide opportunities to learn from others with the same condition. These technologies include mobile health technologies (or mHealth, which is the use of mobile devices to support a health practice (World Health Organization, 2011a)), telemonitoring technologies (transmitting data about health between geographically separated individuals (Maric et al., 2009)), and wearable technologies (devices worn on the body that produce data about the wearer or their surroundings (Piwek et al., 2016)). In short, how technology can be used to support self-management and self-care has been a prominent area of interest within HCI research.

Understanding how technology can support the everyday self-management and self-care practices of people with COPD is an area which has been relatively unex-

plored in previous research[9]. When research on COPD has been explored in this area, machine learning research studies have dominated. These machine learning studies have largely involved using techniques to predict exacerbations or deterioration of chronic respiratory conditions at home through sensor technology (Anastasiou et al., 2018; Chatterjee et al., 2019; Fernandez-Granero et al., 2018; Gokalp and Clarke; Hofer et al., 2015; Larson et al., 2012; Merone et al., 2014, 2016; Nathan et al., 2019a,b). For example, these studies have accurately predicted exacerbations or respiratory difficulty using pulse oximeter[10] and heart rate readings (Gokalp and Clarke; Merone et al., 2014, 2016), home-based spirometry readings (Anastasiou et al., 2018; Larson et al., 2012), and voice and respiratory acoustics (such as wheezing, breathing, and talking) (Chatterjee et al., 2019; Fernandez-Granero et al., 2018; Nathan et al., 2019a,b).

For example, Anastasiou et al. (2018) created an mHealth system for monitoring and predicting asthma exacerbations seven days in advance through machine learning. The system provides a way for HCPs to passively monitor the patient's status during an exacerbation period, using parameters such as medication usage, peak flow readings, and daily responses to a clinical questionnaire. A different approach was taken by Chatterjee et al. (2019) to detect respiratory deterioration, as they created a wearable device to monitor COPD and asthma patients' abnormal lung sounds, such as wheezing. Their system used machine learning techniques to characterise patients' wheezing as either 'high severity' or 'low severity', which can be used to indicate the severity of their condition. Though these techniques demonstrate clear potential for supporting the detection of condition decline in COPD, these studies focus on the

[9] Nunes et al.'s (2015) review of 29 HCI papers on self-care only included two papers on COPD self-management.

[10] A pulse oximeter is a small digital device that non-invasively measures your oxygen saturation levels (i.e. the oxygen levels in your blood). The result is indicated as a percentage, with a healthy person's reading usually being between 95-100% (British Lung Foundation, 2020).

technical feasibility and accuracy of algorithms compared to understanding patients' needs in the first instance.

The HCI studies that have focused on designing technology for COPD have looked to support patients in practicing rehabilitative and breathing exercises (Pereira et al., 2016), some of which have included HCPs in the process where they can directly support the patient (Spina et al., 2013; Taylor et al., 2011). For example, Taylor et al. (2011) examined how people with moderate to severe COPD who live far from clinics can participate in pulmonary rehabilitation (PR) classes at home. They developed a home-based PR programme using video conferencing technology, reporting clinical improvements for all four participants enrolled onto the study (compared to traditional PR programmes). This intervention addresses an important challenge about the accessibility of essential interventions for people with COPD. However, the study focused on the creation of a therapist-supported tool to make existing rehabilitation classes more accessible; it does not widen our understanding about COPD self-management outside of supervised support.

Similarly, Spina et al. (2013) created an mHealth app that uses sensors to support people with COPD (and cardiovascular disease) to exercise, by providing real time corrective feedback on performance. They tested the system with seven COPD patients under supervision of a therapist, asking them to conduct exercises while using the system. They found that patients were often able to correct their exercises as a result of the system's feedback. The study provided a proof of concept about the feasibility of using smartphone sensors to support exercise in COPD patients. However, it did not evaluate how this technology is being used in practice by patients and how it may be supporting COPD self-management more widely.

Pereira et al. (2016) designed an exercise mHealth app that could be used by people with COPD without supervised support. The app created rehabilitative exercise sessions and allowed patients to share their exercise data with caregivers and on social networking websites. The app was evaluated by 10 participants in terms of how well they could navigate the app, complete tasks, and their overall experience of using it. Participants noted the app's features were useful. However, the study only collected

basic data on user experience, which lacks insight into how participants could envisage using the app beyond the study to support their self-management. Moreover, it does not explore the acceptability of sharing exercise data or where this design decision came from.

A limited number of computer science studies (within and outside of HCI research) have explored other types of technologies to support COPD self-management. For example, improving air quality in the home for people with chronic respiratory conditions (Kim and Paulos, 2009), and tracking parameters such as their symptoms, activity levels, and environment (Beattie et al., 2014; Brunschwiler et al., 2017; Johnston et al., 2009). However, even fewer of these studies appear to have actively involved people with COPD to understand their needs in a capacity beyond testing the technical validity of the technology (Beattie et al., 2014; Johnston et al., 2009).

For example, Kim and Paulos (2009) created the inAir tool to measure, visualise, and educate people with chronic respiratory conditions about the air quality in their homes. They used an air quality sensor, iPod Touch, and a microcontroller to count the particles in the air which creates visualisations on the iPod Touch. They conducted a user study involving five households for a two week period to engage with the inAir tool. They found the visualisations improved participants' awareness of air quality in their homes, and motivated them to improve the air quality. Though the tool helped participants to learn about, and reflect on, air quality, they did not appear to recruit people with chronic respiratory conditions in the user study to understand how this may benefit or impact their health.

Brunschwiler et al. (2017) created an mHealth intervention tool to track numerous parameters that can inform COPD patients about their health. For example, they used the camera and microphone on a smartphone to detect sputum colour changes and coughing; a smart inhaler to track medication adherence; a smart spirometry to track lung function; an activity and vital sign monitor to capture data on the patient's vital signs and energy expenditure; and environmental sensors to detect characteristics about the room the patient is in. The system uses a virtual assistant to provide the patient with information on their condition and reminders to track their symptoms.

They noted the parameters that they chose to track have been grounded in previous work, such as physical activity being a predictor for COPD exacerbations. However, to date, the system has not been trialled with any patients and there is no feedback about the effectiveness of the system for enhancing self-management.

Beattie et al. (2014) created the COPD Activity Lifestyle Support (CALS) system. The system collects and displays a variety of information relevant for self-management. CALS collects how the patient is feeling through a questionnaire, physiological data, sleep data, and has features to support activity goal setting and provide educational material about COPD. The design of CALS was based on patients' needs which were identified through a secondary analysis of existing literature. They included HCPs in the design of the tool, and feedback from patients during trials of the tool. However, the design process involving HCPs and patients is underreported in their work, with no explicit mention of how they were involved and their feedback (Beattie et al., 2014). Moreover, follow up studies detailing how the CALS system has been used by patients have not yet been published.

Finally, Johnston et al. (2009) involved COPD patients in the design of a tool to support collaborative monitoring of respiratory symptoms and exercises. They first interviewed eight COPD patients to understand their experience having used technology to manage their breathlessness through education, exercise, peer interaction, and nurse support. The researchers then used this perspective to create prototypes of their monitoring tool before conducting usability testing with three COPD patients. They found that patients responded positively to the tool, though visualising symptom data prompted a negative reaction from one participant, who preferred not to think about their symptoms each day. Though the study took a user-centered design approach that considered the perspectives of COPD patients, the paper mainly focused on usability of the system and did not discuss user needs in detail. However, they did note that their tool was designed for an 'average user' and future work should consider tools that are more reflective of the heterogeneous COPD population.

As shown, some studies have focused on designing and building technology to support COPD by enabling the detection of exacerbations, rehabilitative exercises,

awareness of air quality in the home, and tracking numerous physiological and environmental parameters. Most of the examined literature focused on testing the feasibility and validity of a pre-conceived intervention tool, or have designed tools that have a clinical focus. However, there is a need to understand the wider context of COPD self-care as a starting point so that technology can be designed with people's specific needs at the forefront. Self-care is not a passive activity, but an active combination of important processes that the individual will undertake to improve their wellbeing (Nunes and Fitzpatrick, 2018). COPD self-care is rooted in the social, physical, and emotional difficulties faced by the individual, which can affect their desire and motivation to fulfill certain self-care practices (Cicutto et al., 2004).

It is important to understand what technologies individuals may find valuable to support daily living with COPD, and how they may integrate these technologies into their lives. In their review of self-care technologies in HCI, Nunes et al. (2015) highlighted the importance of focusing on non-medical aspects of a person's condition, to consider a more holistic picture of what self-care looks like in reality. This thesis aims to address these limitations in the literature by underpinning the lived challenges that people with COPD face, through actively collaborating with them to answer my research questions. Ultimately this will answer my second research question: 'what is the lived experience of COPD, and how can technology support this experience?' Once this is better understood through involving people with COPD directly in research, researchers and designers will be more knowledgeable about how technology could support their real needs.

2.6 Personal Health Data for Data Supported Decision-Making

While the previous sections focused on DSDM technologies for clinical decision-making and technologies to support COPD self-management, this section focuses on uniting these activities to enable DSDM for ongoing COPD care. Technology can

enable DSDM by supporting patients to track and monitor their symptoms outside of clinic settings, which they can then share with people in their care circle (such as their HCPs or caregivers) (Cohen et al., 2016; Pang et al., 2013). 'Self-monitoring' or 'self-tracking' refers to the conscious recording of specific features in a person's life (such as features about their health) (Lupton, 2014b). The self-monitoring process may be a patient or clinician initiated process (Zhu et al., 2016), meaning that the patient may decide themselves that they wish to self-monitor their symptoms or may so do at the advice of a clinician. The data can then be used to support decision-making about care, such as by personalising self-management plans; considering specific interventions; goal setting; or changing medications (Chung et al., 2016; Mentis et al., 2017; Schroeder et al., 2017; Zhu et al., 2016). Though this data can be shared with different people in the patient's care circle, this section focuses specifically on sharing this data with HCPs for DSDM (Holman and Lorig, 2000).

Personal health data is collected by individuals so they can understand, and reflect on, characteristics about their health (Li et al., 2010; Rapp and Cena, 2016). When this data is shared and used within clinical contexts, it is described as 'patient-generated data' (Shapiro et al., 2012). This data can be viewed collaboratively in clinic settings, such as when patients bring paper-based or digitally self-tracked data about their condition to appointments with their HCPs (Chung et al., 2016; Mentis et al., 2017; Schroeder et al., 2017; West et al., 2016, 2018). It can also be shared remotely with HCPs through practices such as telemonitoring. During the telemonitoring process, patients will use equipment provided by their healthcare provider to monitor predetermined variables about their health, which are sent to the HCP. The HCP will then view and interpret the data, making contact with the patient in instances where there are outliers. In both instances of sharing patient-generated data (in clinic settings and remotely), HCPs have an active role in viewing the data to consider its meaning in context to the patient and their management.

Understanding the self-monitoring process as experienced by patients themselves is important for exploring how technology may support and enhance this practice. In-the-wild studies are a particularly valuable way to explore this, as they provide

organic insights into the patients' experiences of engaging with the self-monitoring process (Klasnja et al., 2011; Mamykina et al., 2015; Rogers et al., 2013). When patient-generated data is shared with HCPs for decision-making, it is additionally important to explore their experiences of receiving this data. Incorporating the HCPs' perspective alongside the patients' is key for understanding how patient-generated data could be feasibly used in practice to support collaborative self-management and DSDM. This full picture understanding can help researchers consider the potentially different requirements that patients and HCPs will have for this process.

The practice of self-monitoring health conditions has been of strong interest to the HCI community (Bardram et al., 2012; Ferrario et al., 2017; Gronvall and Verdezoto, 2013; Kim et al., 2019; Lupton, 2013; Mishra et al., 2019; Nunes et al., 2015; Schroeder et al., 2017; Vega et al., 2018). However, studies reporting the experiences of self-monitoring COPD symptoms specifically is fairly scant within previous work (both within and outside of HCI research) (Brunton et al., 2015; Dahl et al., 2018; Huniche et al., 2013; Nadarajah et al., 2019). Some studies in this space have focused on the creation of novel technologies that can support self-monitoring of COPD, rather than exploring how these technologies are used and experienced by people with the condition (Hofer et al., 2015; Larson et al., 2012; Xu et al., 2013).

The studies that do explore patient experiences of self-monitoring their COPD have focused primarily on telemonitoring contexts (Brunton et al., 2015; Dahl et al., 2018; Huniche et al., 2013; Nadarajah et al., 2019). For example, Nadarajah et al. (2019) explored self-tracking needs and concerns of six COPD patients in a telemonitoring context. Patients participated in telemonitoring to track objective and subjective data three times a week for at least three months, including: pulse rate, oxygen saturation levels, weight, and questions about symptoms. Hospital staff made contact with patients on occasions where data deviated from patients' normal range. The study reported that patients were motivated to track their symptoms as they felt a sense of security that HCPs were connected in the process. However, they noted that patients opted to under-report their symptoms when they were unsure how their symptoms compared to their usual baseline. Moreover, patients could not report

what they learnt from self-monitoring their symptoms as they did not have access to their own data throughout the study. Though the study provided valuable insights into the patient experience of self-monitoring (as a process), the study was limited in that the patients were not able to use the data to enhance their self-management. Moreover, the HCPs' perspectives were not explored in the study.

Dahl et al. (2018) uncovered similar findings to Nadarajah et al. (2019), their study focused on the values and tensions that emerge through the process of telemonitoring – with an emphasis on patient safety. They interviewed both COPD patients and HCPs about their experiences participating in a telemonitoring intervention. Patients used a web-based questionnaire where they rated their symptoms for 10 weeks, and if their symptoms appeared aggravated they received a call from a HCP. The study reported that patients felt positive about the intervention, and placed value in the added safety of the HCPs' involvement. However, they also found that patients under-reported their symptoms to avoid 'burdening' the HCPs. The HCPs thought the telemonitoring process was beneficial as patients had become more active in their own management. However, HCPs were concerned about how to interpret irregular or underreported data, and highlighted the additional work involved in providing support to patients over the phone during the study. This study takes a full picture perspective by exploring the experiences of both patients and HCPs. However, the study focused on patient safety, and while this is an important perspective, there is an opportunity to extend this research by considering broader factors outside of this lens. This can help to build a stronger understanding of the COPD self-monitoring process, and how patient-generated data may contribute to DSDM in practice.

Brunton et al. (2015) reviewed 10 papers (relating to seven studies, five of which were randomised control trials[11]) which qualitatively evaluated the patient and

[11] Randomised control trials of technology in this context usually involves assigning participants to one of two groups, one exposing the participant to the intervention (in this case, the clinical system) or the second 'control group' (utilising conventional care without the system). The system's impact is then studied (Liu and Wyatt, 2011).

HCP experience of COPD telemonitoring studies (only three studies explored both perspectives). They reported three prevailing themes relating to user experience across the seven studies. The first was how telemonitoring helped to validate patients' health concerns which encouraged them to seek help when needed. Though one study reported concerns from HCPs that telemonitoring may promote patients to become fixated on the data and dependent on HCPs during periods of ill health (Fairbrother et al., 2013). Some studies reported that patients used the data that they had generated to enhance their self-care independently.

The second theme related to the change in interactions between the patient and HCP, as telemonitoring changed the type of contact (face-to-face to remote) and the frequency (periodically to daily). Patients reported feeling reassured by having more regular contact with HCPs, and a 'sense of security' knowing their data was being viewed remotely. Though patients viewed the change in interactions positively, three of the seven studies showed that HCPs had a less favourable experience as they lost the social and physical context required for a holistic view of care.

The third and final theme related to how telemonitoring transformed the nature of care work. Patients felt empowered, and welcomed taking a more active role in their care by conducting monitoring activities typically undertaken by their HCP. Whereas HCPs reported how telemonitoring increased their workload, due to additional contact with patients and expectations to install, and deal with, study equipment.

The review by Brunton et al. (2015) synthesised important conceptual insights into the positive and negative experiences of COPD telemonitoring. They called on future work to expand on this limited body of literature by qualitatively exploring how positive experiences are inhibited through telemonitoring. They also discussed the value of focusing on how specific *types* of technology interventions may increase patient self-management and user acceptance. This was raised as they acknowledged that their study focused on *experiences*, without considering the specific technologies used within the studies they had evaluated.

Overall, there are limited studies that explore the experiences of COPD self-

monitoring. The majority of studies have focused on telemonitoring, and have not analysed findings about the self-monitoring experience in light of technology (re)design. From a HCI standpoint, there is a need to explore the experiences of the COPD self-monitoring from the perspectives of both HCPs and patients to understand how this can inform design. This exploration allows for a stronger understanding of experiences specific to COPD care, a prevalent chronic condition that requires ongoing collaborative management (Barton et al., 2015; Kuzma et al., 2008). This thesis aims to address this gap in the literature by answering the third research question: 'what is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals?' Once this is better understood, it will inform how self-monitoring technologies should be designed, ensuring that both perspectives are accounted for. This will support future solutions that aim to be integrated as part of COPD care in practice.

2.7 Chapter Summary

This chapter has provided a contextual understanding of COPD, including the complexities of diagnosis, ongoing management of the condition, followed by experiences of living with the condition. Then, I explored the concept of DSDM in healthcare, which sets the tone for the remainder of this thesis. I reviewed the current literature around DSDM technologies for clinical decision-making (with a focus on dashboards), technologies for supporting self-management of COPD, and self-monitoring of COPD symptoms. The gaps identified in the literature provided motivation for the three research studies (Chapter 4, 5, and 6). Before introducing these studies, the next chapter will present the methodology for this thesis.

Chapter 3

Methodology

This chapter provides a description and justification of the research methodology for this thesis. It begins by describing the methodological approach that this thesis follows. Then I introduce and discuss my qualitative research method and data analysis approach. Following this I introduce the healthcare setting that research chapters 4 and 6 took place in. This leads to a discussion of the research participants and their recruitment, including the challenges faced with recruitment. Next, I move on to discuss the ethical considerations of this thesis. Finally, I conclude this chapter by discussing the salient limitations arising from this research methodology.

3.1 Methodological Approach

This thesis takes a mixed methods approach. Mixed methods research involves a combination of different research methods. For example, it can include the use of both qualitative and quantitative methods (Doyle et al., 2009), or a combination of methods within one specific methodological paradigm (Johnson et al., 2007b). The research in this thesis is mostly qualitative, mainly incorporating multiple qualitative methods and approaches for data collection. Before moving onto the specific data

collection methods, it is important to first discuss the underpinnings of the main methodological approaches used for this research.

The aim of this thesis is to understand the role that data supported decision-making (DSDM) technology could have for Chronic Obstructive Pulmonary Disease (COPD) care. I take an exploratory design-oriented research approach to achieve this. Design-oriented research seeks to produce new knowledge by involving design activities within the research process (Fallman, 2003, 2007). What is primarily contributed from the process is knowledge arising from studying artifacts and ideas, rather than producing 'final' products (Fallman, 2007). The research in this thesis follows a number of different user-focused frameworks and processes to produce new knowledge. The goal is to explore the different contexts, experiences, and needs involved with COPD care. Therefore, it is appropriate to utilise different methodological frameworks and techniques to explore these diverse areas of focus. I discuss and compare the different frameworks and approaches used throughout this thesis below. These are: user-centred design, human-centred design, and participatory design.

User-centred design (UCD) is a framework used in Human-Computer Interaction (HCI) research that emphasises the importance of focusing on the target user's needs at each stage of the design process. Its principles are drawn from numerous diverse fields, including computer science, engineering, psychology, anthropology, and sociology (Ritter et al., 2014). The key to designing user-centred systems is possessing not only knowledge of technology, but knowledge of people. Norman and Draper's seminal work in 1986 helped change thinking about system design. They proposed a pluralistic approach to designing computer systems, with a focus on the target user as a starting point of systems design. This contrasted with prior approaches that solely focused on designing systems that achieved their functional purpose as the goal.

Specifically, Norman and Draper (1986) discussed the importance of designing systems that consider how psychological goals and user intentions can map onto physical variables of a task on a system. In doing so, systems can be designed that create 'pleasurable engagement' (p.32) in their use (Norman and Draper, 1986). These discussions by Norman and Draper (1986) laid the foundations for UCD. What distin-

guishes UCD from other user-focused frameworks is that it has defined boundaries between the designer and the user (Sanders and Stappers, 2008). The focus is on the user whose needs must be understood and satisfied by the designer. However, there are still a plethora of opportunities in which end users can collaborate with designers in the UCD process. Collaboration can occur during requirements engineering, prototyping, user testing, and evaluation (Noyes and Baber, 1999).

Human-centred design (HCD) is a user-focused framework that focuses more explicitly on how systems can have a direct impact on people's *contexts* and *capabilities* (Ritter et al., 2014). Compared to UCD, HCD takes a more holistic consideration of people's needs. Gould and Lewis (1985) outlined three core principles of HCD. The first involves focusing on users and tasks. That is not just *identifying* their needs, but *understanding* the nature of their work, behaviour, and attitudes. The second principle involves empirical measurement, emphasising the importance of user testing of prototypes for observation and tuning. The third principle involves adopting an iterative design approach which repeats the previous principles as often as needed. The emphasis of HCD is on the ways in which technology can change contexts and activities both within and outside of its use (Ritter et al., 2014). Although elements of HCD apply to UCD and vice-versa, their key focuses subtly differ.

Participatory design approaches describe methods that promote collaboration between end users and designers (Carroll and Rosson, 2007). These methods can be used within UCD and HCD frameworks. Participatory design emerged initially as an approach to explore how technology could impact the day-to-day activities of workers. The focus on the workplace arose from the desire to build emancipatory technological solutions that could support workers to carry out their duties (Bødker et al., 2000; Kraft and Bansler, 1994). A narrative was then introduced that workers should be involved in decision-making about how technology is used in the workplace. One notable participatory design project in healthcare was project Florence, an empowering feat providing nurses with the ability to influence the design of computer systems that form part of their daily work (Bjerknes and Bratteteig, 1987). Of relevance to the discussion on participatory design and empowerment are the tensions observed in recent years

about the role of technology in healthcare. Specifically the advancing role of artificial intelligence in clinical care (particularly decision support systems), with concerns about the prospect of technology 'replacing' clinicians through automation (Foley, 2016; Hannah Devlin, 2018; Mazouè, 1990; Shortliffe, 1993).

Participatory design is similar to co-design, which is also an approach that involves users being embedded in the design process. In fact, Sanders and Stappers (2008) have argued that participatory design is the same as co-design. However, some scholars have argued that there are subtle differences between the two (Cantu and Selloni, 2013; Langley, 2016; Spagnoli et al., 2019). For example, Langley (2016) argued that although co-design enables the involvement of others to contribute to the design process, the researcher ultimately holds an 'expert' role as they manage and own the process. This is in contrast to participatory design, which Langley (2016) described as offering more power, democracy, and ownership to participants in the design process (i.e. rooted in the origins of the approach described previously). When discussing the approaches used in this thesis, I subscribe to the distinction that participatory design affords participants a stronger sense of ownership in the design process (Cantu and Selloni, 2013; Langley, 2016; Spagnoli et al., 2019).

Table 3.1 summarises the approaches used within each research chapter.

Research Chapter and Short Title	Aim	Description of Approaches	
Data Supported Decision-Making (Chapter 4)	Exploring DSDM for COPD in clinic settings, realised through the design of a DSDM prototype.	UCD	Study followed a UCD process to design a DSDM prototype, overall led and managed by me (researcher)
		HCD	Broader effort employed to understand the nature of healthcare work and context of care (beyond the specific tasks the prototype should satisfy)
		Participatory design	Stages of the UCD process actively involved HCPs to decide design direction
Technology and the Lived Experience (Chapter 5)	Exploring the lived experience of CRCs and how technology could support this experience	HCD	Sought to explore the lived experience of CRCs, by understanding the context of self-care, and perspectives on, and uses of, technology
Self-Monitoring and Collaboration (Chapter 6)	Exploring the lived experience of self-monitoring symptoms and sharing this data with HCPs	HCD	Sought to examine the organic experiences of self-monitoring and sharing symptom data. A particular focus on how this relates to the wider context of self-management and patient management.

Table 3.1: An overview of each research chapter and approaches used.

3.2 Research Method

The research presented in this thesis largely takes an inductive qualitative approach, an exploratory approach that aims to seek meaning from collected data. Qualitative research is a method in which the researcher actively engages in naturalistic inquiry of real-world settings to collect and interpret data (Lincoln, 2007). By doing so, the researcher becomes integrated into the research process in a similar way as the participants (Corbin et al., 2015; Jackson et al., 2007; Lincoln, 2007; Patton, 2005). Qualitative research is usually employed as a method to explore research questions that seek to understand the rich human experiences of some phenomena, process, or perspective (Caelli et al., 2003; Corbin et al., 2015). It does not involve the collection of data with the intention to test some predetermined hypothesis. Rather, the researcher analyses the raw data to understand the prominent themes which are generated from it, building an understanding of the studied phenomena (Thomas, 2006).

I took an inductive approach as my research questions were exploratory in nature and were not centred around a set of assumptions. More specifically I was interested to explore how DSDM technologies could support COPD care from the perspectives of healthcare professionals (HCPs) and people with the condition. These investigations were designed to be open and exploratory. To identify opportunities for technology to support both participant groups, I had to explore their different contexts and care practices. The very nature of this inquiry was exploratory and interpretive, and as such warranted an inductive approach to the research.

Given this approach, the epistemological position of this thesis aligns with interpretivism, but also draws on pragmatism. Interpretivism focuses on how knowledge is socially constructed by individuals based on their lived experiences (Abdul Rehman and Alharthi, 2016; Doyle et al., 2009; Gray, 2014). This is appropriate for exploring the lived experiences of COPD and how technology can support this experience. Interpretive approaches seek to capture the rich, subjective, and situated experiences of a particular phenomenon from the perspective of the research participants (Doyle et al., 2009; Duarte and Baranauskas, 2016; Saks and Allsop, 2012). This contrasts

with positivist paradigms, which typically dominate health research, which focus on the generation of objective scientific facts and patterns through quantification (Doyle et al., 2009; Saks and Allsop, 2012). Pragmatism, however, employs a mixed methods approach by *blending* qualitative and quantitative paradigms to strengthen research findings (Johnson and Onwuegbuzie, 2004). A mixed methods approach is important for this research, enabling me to contextualise the subjective lived experiences of COPD with the objective quantifiable 'facts' about the condition. Therefore, this thesis aligns with both interpretivism and pragmatism paradigms.

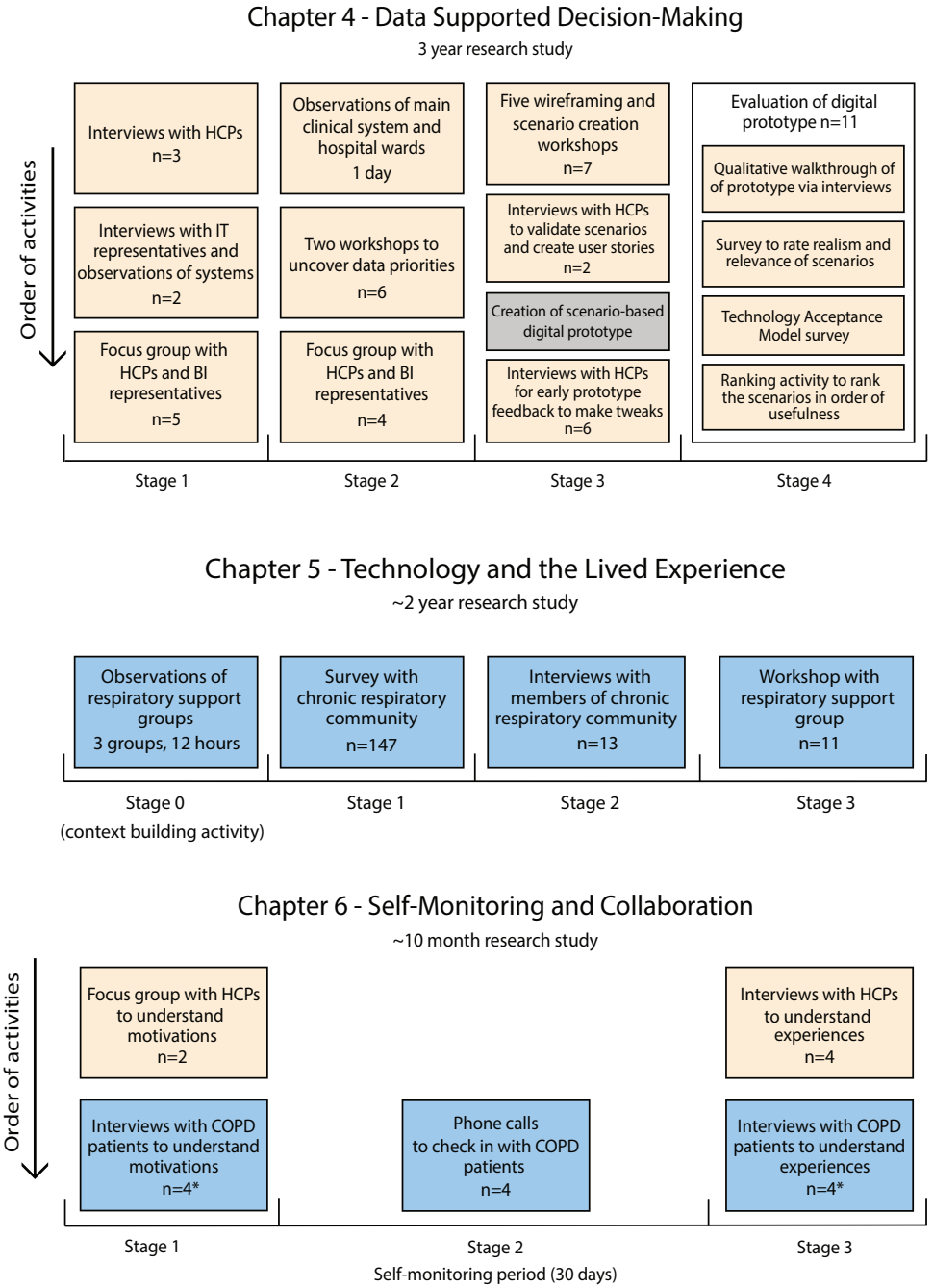
Table 3.2 presents an overview of the individual research chapters, their research question, frameworks used, participants, and specific methods. The specific methods used are discussed in detail within each research chapter. Note that although this thesis is largely qualitative, there are also quantitative data collection methods employed (e.g. quantitative data captured within surveys and questionnaires). Quantitative data was mainly used to supplement the richer qualitative findings. A timeline of each research study and its methods is presented in Figure 3.1.

Research Chapter and Short Title	Research question	Framework	Participants	Methods
Data Supported Decision-Making (Chapter 4)	How can technology support healthcare professionals in their decision-making for COPD care?	UCD HCD Participatory Design	HCPs (n=11), BI representatives (n=3) IT representatives (n=3)	Interviews, observations, focus groups, workshops, scenario-based design, user stories, evaluations, questionnaires
Technology and the Lived Experience (Chapter 5)	What is the lived experience of COPD, and how can technology support this experience?	HCD	People with CRCs (n=170) Carers (n=1)	Survey, interviews, workshop
Self-Monitoring and Collaboration (Chapter 6)	What is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals?	HCD	HCPs (n=4) COPD patients (n=4) Carers (n=1)	Case study, focus group, interviews, phone calls

Note: healthcare professional (HCP), information technology (IT), business intelligence (BI), chronic respiratory conditions (CRCs).

Although each chapter is shown to primarily investigate one research question, as shown in Chapter 1 (Introduction), each research chapter contributes to multiple research questions.

Table 3.2: An overview of the research chapters, research questions, frameworks, participants, and methods.



Note: healthcare professional (HCP), information technology (IT), business intelligence (BI). Blue boxes represent activities undertaken with the chronic respiratory conditions community / COPD patients. Orange boxes represent activities undertaken with HCPs.

Figure 3.1: A timeline of each research study.

3.3 Data Analysis

Interviews, focus groups, and workshops were all audio recorded using a dictation device (with written or verbal consent from the participants). I transcribed each audio recording verbatim, and created memos of early concepts which seemed interesting to explore through future research activities or when analysing the dataset (Birks et al., 2008; Braun and Clarke, 2006). Observations, however, were not audio recorded. Instead I made detailed notes either during or after the observation activity. Transcribing audio recordings myself helped contribute to the early analysis of the data, as I was able to capture and interpret the relevant features of talk which contributed to the later stages of analysis (Bailey, 2008; Bird, 2005). I would estimate that I spent over 150 hours overall transcribing data for this thesis[1].

I mainly used an inductive thematic analysis approach to analyse the datasets, which is a common approach for analysing inductive qualitative data (Braun and Clarke, 2006). This involved carefully reading each data item in the dataset in its entirety before conducting any coding, allowing me to gather initial thoughts about any patterns that could be reviewed during later analysis (Braun and Clarke, 2006). After completing a first reading, I approached each data item again and conducted bottom-up open coding of the data at sentence level by hand. I did not use any specialised software to support this process, except for the survey data in Chapter 5 (Technology and the Lived Experience), where I used NVivo to manage the volume of data (Lakeman, 2009). The coding process involved carefully and iteratively reviewing each line of the data item, then assigning individual codes that describe the data to create broader themes describing the entire dataset (Corbin and Strauss, 2014).

When analysing the survey data for Chapter 5, I analysed the free-text responses using an inductive content analysis approach by hand (Hsiu-Fang and Shannon, 2005;

[1] Researchers have estimated that one hour of audio can take around four hours to transcribe (Stuckey, 2014).

Vaismoradi et al., 2013). This involved first reading through the survey responses, question by question, to familiarise myself with the data. Then, for each question, I identified themes and patterns within the responses, starting at sentence level and analysing them in context to the question. I kept note of the themes which occurred most frequently in the dataset, creating a strong case for their inclusion in the subsequent analysis (Vaismoradi et al., 2013). Additionally, I used case classifications in NVivo to make comparisons in the survey dataset, comparing attributes such as age, chronic respiratory condition (CRC), and length of time living with the condition, to explore any notable differences in responses. Case classifications describe groups (or categories) and their attributes (Bazeley and Jackson, 2013). For example, I explored the potential relationship between age groups and devices owned. Note that this was an exploratory step, there were no predetermined hypotheses regarding how demographic or contextual information may map to particular response types.

The data was analysed throughout the research. To validate the themes created from the data, I discussed them with my supervisors (Dr Maria Angela Ferrario and Dr Roisin McNaney). I also carried out member checking of early themes and findings with the participants throughout the research. I carefully judged whether I had reached data saturation by considering the richness (quality) and thickness (quantity) of the dataset (Fusch and Ness, 2015). I tried to strike a balance between collecting data that was both rich and thick, with a priority for the former (Saunders et al., 2018). In instances where data saturation was not yet reached, I undertook further research to collect more data on areas which required saturation. I achieved data saturation for all three research studies, which indicated that I could cease data collection.

3.4 Healthcare Setting

Before describing the participant recruitment process in the section below, it is useful to briefly describe the healthcare setting which the research for Data Supported Decision-Making (Chapter 4) and Self-Monitoring and Collaboration (Chapter 6) took

place in. All HCP participants recruited for this thesis worked within this setting. Further details about their work practices are included in the research chapters.

This research involved participants from two collaborating National Health Service (NHS) organisations. In England, where this research took place, many healthcare services are managed by types of NHS Trusts. Trusts are organisations which typically provide healthcare services to patients in their region. This can include primary and secondary care services, and sometimes community care services (Department of Health, 2005). Primary care services are the first point of contact for patients, such as General Practitioner (GP) practices, pharmacies, or dentists. Secondary care services are carried out within specialised clinics and hospitals (for example, for inpatient care, where a patient is admitted to hospital for a health related incident). Community care services are diverse and often involve services that help people with complex health needs (though the specific services offered are organisation dependent) (Charles, 2019). For example, community care services may provide support for managing long-term health conditions or services aimed at preventing certain health conditions, such as smoking cessation services (Charles, 2019).

The healthcare staff in this research were either part of a hospital respiratory service or community care respiratory service. The hospital respiratory service is made up of respiratory consultants (senior doctors who have completed specialised training in respiratory health) and COPD nurses (nurses specialised in respiratory health). The hospital team work within a respiratory ward at a hospital. The community care service is made up of COPD nurses, physiotherapists (who specialise in physical methods to treat injuries or diseases), and assistant practitioners (who are trained to assist and deliver health and social care in a specific condition domain). The community team operate in shared office spaces across two healthcare centres located a few miles from the hospital. Both organisations work together to provide respiratory care services to patients in their region, as well as other (non-respiratory) services. How they collaborate to deliver care to COPD patients is discussed in further detail in Chapter 4 (Data Supported Decision-Making).

3.5 Participants and Recruitment

This thesis involved a diverse range of participants. Most participants were people with CRCs or HCPs. However, in Data Supported Decision-Making (Chapter 4), there were also business intelligence (BI) representatives (who direct business strategy), and information technology (IT) representatives (who build, maintain, and train on information technology systems). Their diversity of expertise and perspectives were key for the UCD approach taken in Chapter 4. Likewise there were two carers who participated in Technology and the Lived Experience (Chapter 5) and Self-Monitoring and Collaboration (Chapter 6) respectively. An overview of the research participants included across this thesis, along with the recruitment channels, is shown in Table 3.3. The breakdown of participants are discussed in further detail within each research chapter. There were no monetary incentives offered for research participation.

The remainder of this section discusses my approach to recruiting the main two participant groups: people with CRCs and HCPs. I also discuss the challenges involved with recruiting people with chronic health conditions and HCPs for research.

Research Chapter	Participants	Recruitment Channels
Data Supported Decision-Making (Chapter 4)	HCPs (n=11) BI representatives (n=3) IT representatives (n=3)	All participants from this study were staff members of the two collaborating healthcare organisations (the hospital respiratory service and community care respiratory service). They were recruited through snowball sampling
Technology and the Lived Experience (Chapter 5)	Survey respondents (n=147) Interview (n=13) Workshop (n=11, inc. 1 carer)	Respiratory support groups, Facebook, Reddit, and HealthUnlocked
Self-Monitoring and Collaboration (Chapter 6)	HCPs (n=4) COPD patients (n=4) Carers (n=1)	The HCPs from this study were staff members of the community care respiratory service. The COPD patients were patients of that community care service

Note that three of the HCP participants in Chapter 6 were also participants in Chapter 4.

Table 3.3: Overview of research participants and recruitment channels.

3.5.1 Recruiting Patients and People with Chronic Conditions

Recruiting people as participants in healthcare research has historically been challenging for a number of reasons; mistrust in health research (Corbie-Smith et al., 1999) and limited accessibility due to poor health (Patel et al., 2003) are among some of the reasons. As such, when embarking on this research I anticipated facing difficulty in recruiting people with CRCs. Although I recruited 171 participants from the CRC community in total, the process was challenging for different reasons depending on which research question I was answering. I describe the challenges faced when recruiting participants for Technology and the Lived Experience (Chapter 5) and Self-Monitoring and Collaboration (Chapter 6) below.

3.5.1.1 Recruiting for Technology and the Lived Experience (Chapter 5)

Technology and the Lived Experience (Chapter 5) is made up of a survey (147 participants), one-to-one interviews (13 participants), and one workshop (11 participants). To recruit participants for interviews and the workshop in this chapter, I relied heavily on support from respiratory support groups in North West England. By attending these groups and keeping in contact with them, I was able to build trust with this community and familiarise them with my research. This helped facilitate recruitment. It is important to note that recruiting from support groups can bias research findings. Support group members may have different condition experiences compared to those who do not attend support groups (Hewison and Haines, 2006). For example, people who do not attend support groups may lack social support or face significant symptom related challenges inhibiting them from attending groups — which influences the perspectives captured in the data.

In addition to attending the support groups, I published recruitment material online for interviews through Lancaster University's website and social networking websites. However I was not able to recruit any participants this way. It was clear that building trust with the respiratory community was key to recruitment for face-to-

face research activities, and this resonates with the trust challenges raised in previous healthcare research (Becker et al., 2004; Corbie-Smith et al., 1999; Renert et al., 2013; Silvestre et al., 2006; Sutton et al., 2003).

Trust was also key for recruiting participants to undertake the survey for Technology and the Lived Experience (Chapter 5). The survey was open for 70 days. When advertising the survey, I posted paper versions to four respiratory support groups in North West England (three of which I had been visiting). I provided them with stamps to return the completed surveys to me. I also advertised the survey through email and online using Facebook, Reddit's COPD forum, and the British Lung Foundation channel on HealthUnlocked[2]. Recruiting from specific online communities can be an effective way to reach a large audience, particularly hard to reach populations (Shatz, 2017; Topolovec-Vranic and Natarajan, 2016). However it can also bias research findings as it is likely that people actively engaging in online communities are more computer literate and feel technology has benefits, which is relevant to my investigation of technology use and perspectives among the CRC community (Hamilton and Bowers, 2006). Likewise the responses may reflect individuals who feel more supported as they are connected with others within online communities (similar to those who attend physical support groups).

When I advertised my research on Reddit and HealthUnlocked (which had respiratory communities which I could approach directly), I had to introduce myself, my research, my prior publications, and my current request for participants[3]. Whereas posting my survey link on Facebook (a less community specific social networking medium) required no approvals process and the use of different language. I was not entering a specific online community as such, rather I was making an open call

[2]HealthUnlocked is an online forum made up of individual channels where members can offer and request advice about living with a health condition.

[3]In fact, before I was allowed to post my research on HealthUnlocked, I was required to have my survey participation request approved by a moderator before posting.

for survey participation and for people to share the survey link to their networks. I used unique survey links to track responses across each medium and observed two responses from Facebook, 23 from Reddit, and 89 from HealthUnlocked. There were 33 paper responses sent back from four respiratory support groups.

3.5.1.2 Recruiting for Self-Monitoring and Collaboration (Chapter 6)

Recruiting patients as participants for Self-Monitoring and Collaboration (Chapter 6) was far more challenging. This study involved four patients who used an mHealth app for four weeks as part of a case study. The HCPs had to undertake recruitment for this study as patients needed to meet a set of clinical criteria to participate (that they were clinically well enough to self-monitor their condition independently). Previous work has noted that collaborating with different HCPs can be an accelerator for recruitment (Newington and Metcalfe, 2014). However, for Self-Monitoring and Collaboration, it was still very difficult to recruit participants. One notable reason that recruitment was slow and difficult for this study was that participants were being recruited as 'patients' in the healthcare system (rather than just as 'members of the public with a CRC' as was the case for Chapter 5). Participants had to be recruited this way to explore the lived experience of self-monitoring COPD symptoms and sharing this data with their HCPs. This approach to recruitment required additional ethical approvals (Health Research Authority) before recruitment could commence. I provide further detail on the ethical approval processes in the next section.

During the recruitment process for Self-Monitoring and Collaboration, I asked HCPs to keep a short record of the demographics of patients who declined participation. This record included their gender, age, and reason for decline. I believed this would help to appreciate the barriers to participation. In total 57 COPD patients were approached by four HCPs during clinics or pulmonary rehabilitation classes at the community care site. Only four patients decided to participate. The reasons for 53 patients deciding against participation were:

- Not interested in the study and no further explanation offered (36);

- No smartphone to access the mHealth app (8);
- Reluctant to record health information on the mHealth app (4);
- No internet connection to download and use mHealth app (4);
- No desire to use the internet (1).

Recruitment was open from May 2018 to November 2018. The HCPs provided feedback iteratively throughout the recruitment process about the observed barriers. Once I had learnt that smartphones and lack of internet access was a barrier, I provided the option for patients to borrow a smartphone with a SIM card that had 5GB of cellular data[4]. This change to the study (providing smartphones and SIM cards to patients) required me to submit an amendment to my study protocol to the Health Research Authority. I had to wait for approvals again before the study could continue. Recruitment was therefore on hold for 40 days (June 14th — July 23rd 2018). On July 24th 2018, after the amendment was approved, four participants were recruited. One participant who was recruited was lent a smartphone and SIM card, the other three participants had devices and internet access of their own.

3.5.1.3 Comparing Recruitment Approaches

Technology and the Lived Experience (Chapter 5) and Self-Monitoring and Collaboration (Chapter 6) explored different contexts and required different recruitment approaches. Technology and the Lived Experience sought to explore the lived experience of CRCs and the potential role of technology to support this. The aim was to explore the diverse experiences of the CRC community. This required participants to either participate in a survey, interview, or workshop. I led the recruitment for this

[4]The smartphones and SIM cards were provided by Lancaster University's School of Computing and Communications department.

study, and was able to embed myself in the CRC community to build trust among participants, which facilitated recruitment.

Whereas Self-Monitoring and Collaboration explored a specific context where patients were required to monitor their COPD symptoms. This required ongoing effort and time investment from patients (e.g. compared to an interview). Additionally, HCPs were the study recruiters for Self-Monitoring and Collaboration. They were tasked with identifying potential participants, explaining the study to them, and answering any immediate questions (among their usual clinical duties). The recruitment for Technology and the Lived Experience was undertaken by me and was driven by my motivation to complete the study. The HCPs leading recruitment for Self-Monitoring and Collaboration were understandably not driven by this same motivation.

The different recruitment approaches, required participation level, and barriers to access yielded very different sample sizes for both studies (Technology and the Lived Experience: 171 participants versus Self-Monitoring and Collaboration: four patient participants). Although I do not claim these to be the only reasons for sample size differences, I argue they are strong contributing factors.

3.5.2 Recruiting Healthcare Professionals

Recruiting HCPs as participants has a different set of associated challenges compared to patient participants. It is widely understood that HCPs are extremely time pressured in their day-to-day work, and previous work has shown that HCPs can perceive research participation as being a time burden (Asch et al., 2000; Broyles et al., 2011; Solberg, 2006). There were a total of 12 HCP participants involved this research, 11 participating in Data Supported Decision-Making (Chapter 4) and four in Self-

Monitoring and Collaboration (Chapter 6)[5]. All HCP participants within this study were recruited from the two collaborating NHS organisations described earlier. All participants specialised in respiratory care.

I used snowball sampling to recruit HCPs for both studies (Faugier and Sargeant, 1997; Noy, 2008). Snowball sampling has been shown to be a successful method of recruitment for traditionally hard to reach populations (Asch et al., 2000; Bonevski et al., 2014; Faugier and Sargeant, 1997). Here, I found snowball sampling provided an effective way to identify and approach key staff whose participation would help advance the research aims. For Data Supported Decision-Making, once I had recruited a core group of interested HCPs, they were able to identify and approach potentially interested colleagues to participate. Through being introduced to the HCPs in Data Supported Decision-Making, I learnt about their motivations and interests. This enabled me to directly approach and recruit three HCPs for Self-Monitoring and Collaboration from the same participant pool.

The most challenging part of involving HCPs as participants was not necessarily recruitment itself, but retaining their involvement throughout the research process. As HCPs participated in a UCD process in Data Supported Decision-Making, their consistent involvement was important throughout. All research activities occurred at their place of work. However, I often faced difficulty arranging to meet participants to undertake the various research activities, as they had very limited availability (and were often tired when we did meet). This was particularly challenging from September to March each year, when it was 'flu season' and staff were overwhelmed looking after respiratory patients. Moreover, there were some instances where last minute demands on HCPs' schedules resulted in a no-show to research activities (Broyles et al., 2011; Ingersoll, 1995). Not only did this impact the immediate data collection,

[5]Three of the four HCPs in Self-Monitoring and Collaboration were also participants in Data Supported Decision-Making. The fourth HCP was newly recruited for Self-Monitoring and Collaboration through invitation from the other HCPs.

but introduced delays in the overall research trajectory, as the next opportunity to reschedule the activity was often weeks away. In addition to the challenge of sustaining involvement, some participants were promoted to different roles (and no longer had time to participate in the study) or moved to different organisations. This created challenges for this research, which had to be completed within a limited time frame and relied on long-term engagement.

3.6 Ethical Considerations

Rooted in healthcare research is the long tradition of institutionalised bioethics, arising from various human rights violations that occurred in the twentieth century to advance medicine. As such, it is a requirement that all human subject research undergoes independent ethical review, with an emphasis on obtaining informed consent from participants. Ethical review is usually obtained through an institutional review board of some kind. For the research presented in this thesis, all research chapters were naturally subject to an internal and independent review process at Lancaster University. However, in addition to this, Data Supported Decision-Making (Chapter 4) and Self-Monitoring and Collaboration (Chapter 6) were subject to an extra layer of review by the Health Research Authority (HRA) (Whitburn et al., 2017).

The HRA are a national body that reviews and regulates health and social care research carried out with an NHS service in the United Kingdom. Depending on the categorisation of the research, there may be further layers of approval required beyond standard HRA approval. For example, there is an additional layer of ethical approval that must be obtained by the Research Ethics Committee (REC) for any studies which involve patients as participants. The responsibility of the REC is to decide if the research is ethical from the perspective of domain experts and members of the public (the committee vote on the outcome of the application). Self-Monitoring and Collaboration was subject to a review by the REC due to the involvement of NHS patients as participants. Data Supported Decision-Making only required standard HRA

approval as there were no patients as participants.

Obtaining approvals from the HRA and REC introduced significant delays for starting these studies. It is acknowledged among the health research community that these processes are lengthy and complex (Fur; Fistein and Quilligan, 2012; Page and Nyeboer, 2017; Thompson and France, 2010). It is worth noting that these review processes require the submission of information from both the researcher (myself, at Lancaster University) and the research site (the collaborating NHS organisations). This dependency introduced unanticipated delays for beginning Data Supported Decision-Making and Self-Monitoring and Collaboration. I found the approvals process to be heavily geared towards clinical trials or intervention studies, which made writing and navigating the application challenging for my small-scale qualitative research.

After the relevant approvals were secured, the final step was to obtain a research passport. A research passport is an additional process that must be granted before you can enter an NHS premises to conduct any research. This approval is organised by the NHS organisations which are participating in your research, and accounts for your presence on-site to conduct research. Once HRA approval is obtained, and a research passport is secured, the study can commence. It is important to document the ethical review processes for two reasons. First, to demonstrate that this research was independently assessed as being ethical according to its design and aims. Second, to allow the reader of this thesis to appreciate the limitations that these lengthy processes place onto a three and a half year PhD.

3.7 Limitations

This section discusses the limitations which arise from my research design. This includes a discussion on generalisability, validity, and reflexivity.

3.7.1 Generalisability

I argue that this thesis primarily has the potential to generalise through transferability. That is, how the findings of this research can resonate with different settings outside of the original study's contextual confines (Firestone, 1993; Guba and Lincoln, 1989; Hayes, 2011; Polit and Beck, 2010; Smith, 2018). Generalisation based on transferability has been described as a 'collaborative' activity between the researcher and the audience of the work, it is not something the researcher can simply claim with certainty (Polit and Beck, 2010; Smith, 2018). The reader of the research must decide how, and if, the experiential account can be extrapolated elsewhere (both to similar or different contexts) (Hellstrom, 2008; Polit and Beck, 2010).

For example, the reader of this research may find that the concept of how trust effects how HCPs engage with data in Data Supported Decision-Making (Chapter 4) can be seen in health domains outside of respiratory care, or exists when engaging with technology other than a dashboard (Chapter 4, section 4.5.1, pg. 130). It could be the case that the reader identifies transferability across non-healthcare related domains that have similar patterns of work in collaborative teams. I reflect on specific implications for generalisability at the end of each research chapter, though I share my overarching arguments for the thesis as a whole below.

In qualitative research, generalisability is not discussed in the statistical probabilistic sense (Baskerville and Lee, 1999; Crabtree et al., 2013; Guba and Lincoln, 1989; Lincoln, 2007; Yardley, 2000; Yin, 1994) and thus does not equate generalisability with large sample sizes (Crabtree et al., 2013). Instead, generalisability in qualitative research can be achieved providing that the data is rich, meaningful, and thick to facilitate transferability and analytical generalisation (Firestone, 1993; Polit and Beck, 2010; Smith, 2018). Below I describe the steps that I have taken to ensure that my data is rich, thick, and meaningful.

I achieved *data richness* through data and methodological triangulation (Fusch and Ness, 2015). For data triangulation, I involved different types of participants to investigate my research questions (consultants, nurses, assistant practitioners, phys-

iotherapists, IT representatives, BI representatives, people with CRCs, and carers). For methodological triangulation, I have used an array of research methods to capture my findings (interviews, focus groups, surveys, observations, questionnaires, phone calls, workshops, user stories, scenario-based design, and a case study). I have collected *meaningful data* through building my findings from a series of long-term encounters with my participants. I argue this has led to nuanced and detailed findings. I reflect on my relationship with the participants, which has been central to capturing rich and meaningful data, later in this chapter. Finally, through involving a range of research methods and participants, I have collected a *thick* qualitative dataset consisting of 228 individual data items. As such, I argue my findings are grounded in data that is both rich, meaningful, and thick. Therefore, I have provided a solid foundation for the readers of this work to participate in the collaborate activity of generalising.

It is important to acknowledge the difficulty of predicting and quantifying the degree of generalisability of this research. Nevertheless, I do not believe that qualitative research must generalise to a specific number of contexts to be considered useful scientific knowledge. For example, my findings may only resonate with a subset of people with COPD or other chronic conditions. I strongly argue that this still contributes valuable scientific knowledge, as it informs our understanding of the different lived experiences of health conditions which can be supported with technology.

3.7.2 Validity

Qualitative research builds a case for validity and reliability of results through the process of triangulation (Fusch and Ness, 2015; Hayes, 2011; Thurmond, 2001). That is, the careful consideration of the methods used to collect and understand data, followed by an assessment of when data saturation has been reached (Fusch and Ness, 2015). This does not necessarily relate to the *quantity* of data collected, but considers its richness and depth (Fusch and Ness, 2015). I have taken a conscious effort to employ methodological and data triangulation to capture different perspectives that strengthen my conclusions (and I acknowledge their respective limitations).

To further validate qualitative findings, Hayes (2011) and Guba and Lincoln (1989) argued that prolonged engagements with a participant group adds layers of trustworthiness to the study's scientific rigor. This is because the researcher develops a deep understanding of the group, which cannot be built through a single encounter (Guba and Lincoln, 1989). Each study involved engaging more than once with the same participant[6], whether through a series of research engagements, member checking, or by updating participants about the research (Guba and Lincoln, 1989).

Data Supported Decision-Making (Chapter 4) involved a prolonged engagement with my HCP participants over three years. Technology and the Lived Experience (Chapter 5) involved a prolonged engagement with the wider CRC community over approximately two years. Though Self-Monitoring and Collaboration (Chapter 6) was comparatively shorter (10 months), I was engaging with three of the same HCP participants from Data Supported Decision-Making. Likewise, for that study, I engaged with the patient participants on three separate occasions throughout the study. Overall, for this thesis I had the opportunity to engage with participants multiple times to clarify aspects of the data during early analysis. I argue this adds to the trustworthiness of my results.

3.7.3 Reflexivity

It is crucial to acknowledge the influence that I had on this research as I became part of the social world that I studied (Berger, 2015; Jootun et al., 2009). There are undoubtedly many subtle biases that I have introduced into the research process, which influence the quality of the data — just by being my self (e.g. how I communicate verbally and non verbally, how I look, and who I am) (Berger, 2015; Blandford, 2013).

[6]Except data collected through the anonymous survey in Technology and the Lived Experience (Chapter 5).

I have taken care to reflect on factors which I think have been particularly important for my data collection, and ultimately, the outcomes of my research. I describe these factors in the following sections, dividing them by participant groups.

3.7.3.1 People with Chronic Respiratory Conditions

While explaining my research to my participants who had COPD, I consciously disclosed to them that I was the daughter of somebody with COPD. I believe disclosing this information helped to break down perceived participant-researcher power structures (Karnieli-Miller et al., 2009). As participants understood that I believed my research was not just *interesting*, but something I deeply cared about and was affected by (as a relative of somebody with the condition), they were more willing to 'accept' me into the respiratory community. When I attended support groups for Technology and the Lived Experience (Chapter 5), I was not there just as a curious researcher, I was also there as a member of the community. When I had planned visits to the groups, the group leaders would announce in their newsletters that '*our friend Helena*' would be attending. It was clear that I was not viewed as an outsider who was simply there to collect data and leave. As such, I believe my personal relationship with COPD helped facilitate the collection of rich and meaningful data for this research.

I believe that my participants' knowledge of my personal relationship with COPD also impacted one-to-one interview dynamics. I argue that participants felt more comfortable sharing their personal experiences with me, knowing that I may be less judgemental of them, compared to somebody who did not have experience of what COPD is like. This was particularly important when discussing stigma and potentially embarrassing and sensitive topics, like soiling oneself from coughing too hard and fear of dying. This is where my partial[7] insider status within the community enabled me to collect the true and raw experiences of living with COPD (Merriam et al., 2001).

[7] Being a healthy woman in my early twenties meant I was not a complete 'insider'.

Though I was a partial insider, I made it clear that participants should recall their experiences to me in their own words, describing them as the very individual experiences that they are. This helped to avoid participants making assumptions about my knowledge, thus avoiding exploring experiences in depth (Allen, 2004). Though this did not stop the odd comment to the effect of *'but surely you know what that's like, with your mum and all'*. There were even times where participants were giving me self-management advice to share with my mother, or requesting advice based on what my mother does to manage her own symptoms. Dealing with this was sometimes challenging, as I had built a rapport with my participants based on trust, but as a researcher I felt anxious to give healthcare 'advice' to my participants even if it seemed trivial. Instead I always emphasised that each person is different and that it was best to ask their HCP if they were struggling with something in particular.

3.7.3.2 Healthcare Professionals

My experience with participants that had COPD can be contrasted with my experience engaging with HCPs. The power dynamics between myself and HCPs seemed more evident, particularly between myself and the respiratory consultants. They were highly trained professionals with plenty of experience with respiratory care, while I was a young computer science student with only a growing knowledge of their domain. Disclosing that my mother had COPD at the start of my research did not seem to effect the relationships I built, or the dialogue I had, with the HCPs. Though it could have been the case that they phrased their language more sensitively when talking about how the condition progresses and what happens to the most unwell patients. However, this is something which I would suspect a HCP is already accustomed to doing when talking to patients and their relatives or carers.

I felt far more like an outsider with this participant group. I largely conducted research activities with them on my own. During my first encounters with HCPs, I was often asked if I was a 'student nurse' conducting some research. When answering that I was a computer science student, I believe HCPs then oriented themselves to

account for the fact that I was an outsider to their domain. For example, there was common understanding which had to be collaboratively built over time, unlike the understanding I shared with my participants with COPD (which partially pre-existed). One instance of this was learning the roles and responsibilities of the different HCPs and how their organisations worked. As the research progressed, this common understanding was built, and HCPs became more familiar and trusting of me. Through building this familiarity and trust, they became more confident to honestly reflect on their experiences and needs in relation to COPD care.

Overall my relationship with the HCPs developed and strengthened over time due to the fact I was an outsider. Whereas my partial insider status with the respiratory community meant my relationship with them was stronger from the beginning.

3.8 Chapter Summary

This chapter introduced the methodological approach for this research. Following this, I presented inductive qualitative research as the main method for this thesis. Then I discussed my inductive thematic analysis approach for data analysis. Next I described the healthcare setting that Chapter 4 (Data Supported Decision-Making) and Chapter 6 (Self-Monitoring and Collaboration) took place in, introducing the hospital respiratory service and community care respiratory service. Then I discussed the participants within this thesis, the recruitment process, and challenges. I moved on to discuss the ethical considerations of this work in relation to the area of healthcare. Finally I concluded by discussing generalisability, validity, and reflexivity in relation to my methodology.

Chapter 4

Understanding Data Supported Decision-Making in Chronic Respiratory Care

The final phases of this project were worked on collaboratively between myself and Dr Adrian Gradinar (a research associate at the time). Although I solely undertook this research, Adrian contributed to this work by building a digital prototype of the dashboard based on my work. However, the research activities, coding and analysis of data, material, and conclusions of this chapter are all my own work. Some of the data and findings from this chapter have been published as a full paper in the 2018 EAI International Conference on Pervasive Computing Technologies for Healthcare (Tendedez et al., 2018)

4.1 Introduction

This chapter explores the concept of data supported care for Chronic Obstructive Pulmonary Disease (COPD) patients. It investigates how a data supported decision-

making (DSDM) dashboard could support healthcare professionals (HCPs) with COPD care. The DSDM dashboard aims to unite HCPs with data that they believe will inform their decision-making about their COPD patients and service. This chapter documents the design and evaluation of a DSDM prototype. The focus is on exploring the opportunities and challenges that DSDM technologies could introduce for everyday clinical decision-making about COPD care. This chapter aims to answer the first research question: 'how can technology support healthcare professionals in their decision-making for COPD care?'

The key contributions of this chapter can be summarised as follows:

1. A detailed account of the real-world daily challenges faced by HCPs relating to their decision-making about COPD care.
2. The concept of trusting data is particularly relevant for DSDM technologies, and influences how willing HCPs are to engage with the data for decision-making. Data must be perceived as originating from reliable 'sources' and 'authors' for it to be considered trustworthy.
3. Integrating DSDM technologies into healthcare settings requires a careful consideration of the relevant protocols and resources which must accommodate how HCPs can respond to the data. Without these protocols and resources, the technology may not be able to positively influence decision-making.
4. Training HCPs on clinical systems is a time-consuming process and there may be reluctance towards formal training. However, training HCPs on DSDM technologies is important to ensure they can confidently draw safe and correct inferences from the data.
5. A scenario-based evaluation is an effective way to conduct early evaluations of DSDM technologies, without requiring a fully integrated system. However, how we adapt evaluation techniques and methods for DSDM technologies, such as the Technology Acceptance Model, requires careful consideration.

4.2 Study Setting

A brief description of the National Health Service (NHS) and the study setting is described in the methodology chapter (Chapter 3, section 3.4, pg. 50). The following sections describe the everyday work of the hospital respiratory service and community care respiratory service, how they collaborate, and their motivation for a DSDM dashboard.

4.2.1 Hospital Respiratory Service

The hospital respiratory service, referred to as the 'Hospital' henceforth, has a dedicated respiratory ward usually occupied by COPD patients. The ward has 32 beds, including non-invasive ventilation beds which provide breathing support to patients. Respiratory consultants, staff nurses, student nurses, healthcare assistants, specialist nurses, and assistant nurse practitioners work on the ward. Each morning, the consultants undertake a ward round, during which they check on each in-patient. During the ward round, consultants are accompanied by a registrar (a trainee consultant), a nurse, and a doctor. They use mobile computers and paper medical notes to facilitate discussions about each patient before visiting them at their bed. Once the ward round is complete, a second ward round is conducted for patients on an 'outlier list'. The outlier list consists of patients admitted to hospital for a respiratory condition but are located on non-respiratory wards. This usually occurs due to capacity constraints on the ward or to treat a patient before breaching specific national targets[1].

Once the ward rounds are completed, the consultants discuss the tasks to be completed for the day with the rest of the healthcare staff. This occurs in a room called the Doctors' Office located on the ward. A whiteboard, which has a list of

[1] In the United Kingdom (UK), this refers to the time frame in which a patient should be seen to, admitted, treated, or discharged, which is within four hours (UK Government, 2017).

the in-patients, is annotated to reflect the discussions between the healthcare staff. During these discussions, the team will address which patients can be discharged that day and which require further investigations. After this meeting, the COPD specialist nurses will then spend the afternoon carrying out these tasks and providing care to the COPD patients. Consultants and doctors will then attend clinic appointments with respiratory out-patients. These out-patients may be referred to them for a respiratory diagnosis or a review after being discharged from hospital.

To conduct their post-meeting duties, the HCPs will access paper and digital systems to find relevant information about the patients to inform their decision-making. This may involve interacting with any of the five hospital systems (depicted in Figure 4.3 later in the chapter). The most used systems are Quadramed (the electronic medical records system used across the entire hospital), a prescription management system (to request and view patients' prescriptions and medication), and Evolve (a digital document archive system that archives patient documents such as hospital discharge letters or general practitioner letters). The challenge with these systems is that they are not interoperable, and the Hospital staff often switch between each system to obtain the combination of information that they need to make decisions about a patient's care.

4.2.2 Community Care Service

The community care service, referred to as 'Community Care' henceforth, is made up of COPD nurses, physiotherapists, and assistant practitioners. The nurses start the day by providing telephone support to COPD patients on their caseload. These may be patients who have just been discharged from hospital after a COPD exacerbation, acutely unwell patients on their intensive home support service, or patients who are being managed by the service for other reasons. During these calls, the nurses check on the patients' COPD and general wellbeing, providing support and encouragement. They then input a summary of each call onto their electronic care record system (which is a system only accessible by their organisation). In the late morning, the nurses will

Figure 4.1: One of Community Care's shared offices.

also prepare for, and then conduct, home visits to patients that are on their intensive home support service. These are the most acutely unwell patients and require frequent contact from HCPs. Patients may be on this service for a short period after a severe exacerbation, or for longer periods if they are palliative or very severe.

Community Care also run clinics and classes, which are usually led by the healthcare team in the afternoon. There are three types of clinics: (1) spirometry clinics, where a HCP has referred a suspected COPD patient to the service for a certified diagnosis; (2) nurse clinics, where a HCP has referred a confirmed COPD patient to the service for further specialised management; or (3) physiotherapy clinics that help a patient with breathing and mobility. There are also pulmonary rehabilitation (PR) classes which run for eight weeks at a time. These are a series of education and exercise classes for people with chronic respiratory conditions. The classes help patients to learn about their condition, how to manage it, and receive encouragement to remain physically active.

4.2.3 Cross-Organisational Collaboration

As both the Hospital and Community Care operate across the same locality, they often care for the same COPD patients. One of the main ways that both organisations collaborate is through provision of care. That is, once a COPD patient has been discharged from the Hospital after an exacerbation, they usually receive follow-up care and support from Community Care. This follow up care may include PR classes or an intensive home support referral. PR would be recommended if the patient needs support to self-manage their condition to prevent future exacerbations. Intensive home support would be recommended if the patient is acutely unwell and can be cared for at home. Similarly, Community Care will liaise with the Hospital if a patient on their caseload has a severe exacerbation and must be referred into hospital.

The organisations also collaborate through documentation. When a patient is discharged from the Hospital and into Community Care, the nurses receive documentation which explain details of the hospitalisation. The nurses will use this information to understand the patient's context so they can manage them accordingly. Likewise, the Hospital may request a patient's notes from Community Care to paint a picture of their history and context for decision-making. Both organisations may also collaborate with the patient's General Practitioner (GP). This includes requesting patient data recorded by the GP, such as spirometry test results or details about COPD related appointments. This is obtained through letters or phone calls to the patient's GP.

As shown, both organisations' role in the care of patients with COPD is collaborative. This collaborative approach is important for the ongoing care and informed management of COPD patients.

4.2.4 Data Supported Decision-Making Dashboard

This research involved engaging with the Hospital and Community Care to design a joint dashboard to support their decision-making about their COPD patients and services. A dashboard is a type of visualisation software, which aggregates data in

personalised ways to produce knowledge and insights for users. In the healthcare domain, for example, dashboards can turn raw data about Emergency Department visits into visualisations that provide an easy understanding about which times the department is busiest. A dashboard was initially chosen for this study as they were familiar to the HCPs and are commonly used across healthcare settings (Dowding et al., 2015). For example, at the Hospital, there is a dashboard used in the cardiac department that visualises basic departmental data about cardiac appointments and admissions. However, this simple dashboard visualises limited data and does not collate data from different organisations. Thus, it is different to the type of dashboard this study will explore.

The organisations were motivated to explore how the aggregation and presentation of pertinent COPD data could support their decision-making. As described above, the HCPs are required to engage with different clinical systems, paper-based records, and other HCPs to obtain needed information. To that end, this study explores how technology could support this process.

4.3 Study Design and Methods

This chapter reports on a four stage study involving participants from both organisations (see Figure 4.2). Data was collected through semi-structured one-to-one interviews, workshops, observations, questionnaires, and focus groups with the participants. The first stage focused on understanding the problem space and motivations for a DSDM dashboard. The second stage aimed to explore and prioritise HCPs' data needs that should be included on the dashboard. The third stage involved wireframing the interface and creating scenarios for the prototype. The fourth stage involved the qualitative evaluation of the prototype with HCPs.

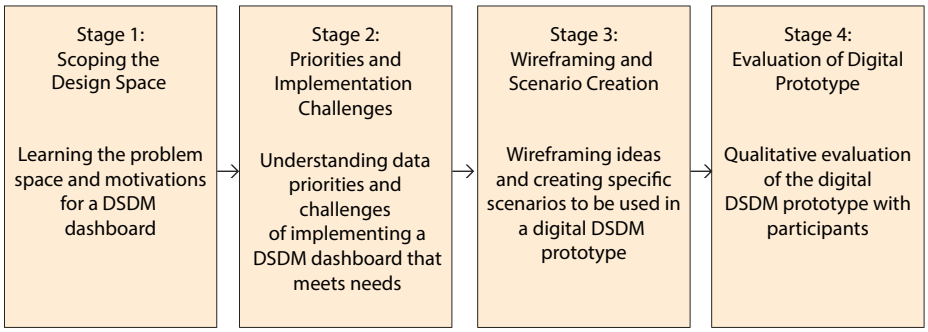


Figure 4.2: The research process within this chapter.

4.3.1 Participants

This study involved 17 participants across both organisations at different parts of the study (Table 4.1). This included 11 respiratory HCPs, 3 Community Care business intelligence (BI) representatives, and 3 Hospital information technology (IT) representatives. Participants were provided with an information sheet and consent form to consider before study participation (provided in Appendix A).

BI staff work within a team of analysts and are responsible for the operational management of services. They use data collected within their organisation to make strategic business decisions about the funding and improvement of services. They have a broad understanding of the types of data that are collected within the organisation. IT staff are responsible for the development, maintenance, and training of the IT systems within their organisation. They assist staff if there is difficulty using a particular system or if a system fails. They have in-depth knowledge of the different systems, what data is collected in them, and what technical solutions could be feasible within the organisation's current technology ecosystem.

Identifier	Role	Organisation
H1	COPD Nurse	Hospital
H2	COPD Nurse	Hospital
H3*	Respiratory Consultant	Hospital
H4*	Respiratory Consultant	Hospital
H5	Respiratory Consultant	Hospital
C6	Lead Respiratory Nurse / Respiratory Service Manager	Community Care
C7*	Lead COPD Nurse	Community Care
C8	COPD Nurse	Community Care
C9*	Lead Physiotherapist	Community Care
C10	Assistant Practitioner	Community Care
C11	COPD Nurse	Community Care
BI1	Business Intelligence and Analytics Manager	Community Care
BI2	Care Group Manager	Community Care
BI3	Business Intelligence Representative	Community Care
IT1	Information Technology Representative	Hospital
IT2	Head of Information and Technology	Hospital
IT3	Clinical Applications Trainer	Hospital

Those prefixed with H are Hospital HCPs, those with C are Community Care HCPs.
Numbers depict participant number, grouped by professional role.
Identifiers with an asterisk (*) represent study leads.
Note that C6 was promoted during the study hence the dual roles listed.

Table 4.1: Chapter 4 participants.

Including different participants groups permits a more inclusive consideration of different levels of expertise, knowledge, and skills which are valuable for exploring this area (Bowen et al., 2011). Moreover, previous work has highlighted that involving

IT staff within the innovation process can help scope technical feasibility and improve dialogue around user needs (Hartswood et al., 2000). Involving BI and IT staff enabled insights into the technical and work-flow feasibility of emerging dashboard designs. They could also contribute unique knowledge about the different types of data and systems across the organisations. This information could not have been effectively obtained through solely involving the HCPs. Therefore, the diversity of participants equipped me with a better understanding of the possibilities and challenges involved with designing and implementing a DSDM dashboard for clinical practice.

At the start of the study, two HCPs from both organisations volunteered to be the study leads (denoted with an asterisk in Table 4.1). The leads were my main point of contact throughout the study, acting as the clinical champion for their organisation. They were committed to being involved in each study stage, and activities were arranged around their schedule. They also helped to schedule sessions with the remainder of the participants.

4.3.2 Stage 1: Scoping the Design Space

The first stage focused on working with participants to understand the problem space and to uncover their motivations for a DSDM dashboard. Three initial one-to-one interviews, each lasting between 30 and 60 minutes, were conducted with the HCPs (H3, H4, and C6) at both clinical sites. The duration of the interviews was dictated by the HCPs' work schedules. The interviews aimed to gain an initial insight into their everyday challenges, and to discuss how they felt a DSDM dashboard could help to address this. The questions revolved around topics such as 'what are your day to day challenges when accessing data in your role?', 'how do you interact with current clinical systems?' and 'how do you believe a dashboard could help to alleviate these challenges?' During the interviews, they discussed challenges with their current clinical systems and high-level key data that they believed having access to would improve the delivery of care and services. These high-level data needs were then

collated into a requirements document[2] (see Appendix B), that was used to stimulate further discussions around data requirements later in this stage.

To gain a better understanding of the main clinical system that was referenced in the interviews, a two-hour interview was conducted with two IT representatives (IT1 and IT2). During this interview, IT2 led a walkthrough of the main clinical system used by the Hospital and Community Care to view a patient's clinical information. This walkthrough was carried out on a testing account which the IT representatives use to train HCPs. An overview of the types of data that the system collects was explored, followed by the process that HCPs would undertake to find certain data about a patient. For example, how to access a patient's latest blood test results and their current hospital admission reason. I was also provided with the IT department's user guide for the main clinical system to deepen my understanding. The interview discussion was focused on sharing the data needs that the HCPs outlined in the prior interviews. We then talked briefly about where this data sits in the main clinical system, followed by data which would be more challenging to obtain as it is not recorded in the system.

The final phase was a focus group at the Community Care site with the broader stakeholder team, including two HCPs (H3 and H4) and three BI representatives (BI1, BI2, and BI3). The objective of the focus group was two-fold: to update the rest of the group about the previous activities (the interview with the HCPs and IT staff) and discuss the initial data needs outlined from the HCPs in more detail, drawing on the insight and expertise of the BI representatives.

The findings from this stage are presented in section 4.4.1 (pg. 94).

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[2]Note that the requirements document was not intended to outline a definitive list of data requirements that would be implemented. At this stage, it was simply used fluidly as a tool to structure early requirements and ideas to probe further discussions.

4.3.3 Stage 2: Priorities and Implementation Challenges

The second stage aimed to understand and prioritise HCPs' data needs, followed by exploring challenges that may arise when implementing a DSDM dashboard. As part of this, it was important to learn more about the different clinical systems outside of the main hospital system. It was also necessary to understand how the main system is used in practice. Although an observation of the main clinical system was conducted in Stage 1, this was in a controlled and quiet environment which does not reflect how the system is used in practice by HCPs. Therefore, I conducted a one day observation at the Hospital with IT3. The day began by IT3 carrying out a walkthrough of the remaining four clinical systems within the technical ecosystem (with a discussion on the sixth, EMIS[3], which was not accessible by IT3). I made handwritten notes throughout the observation. I also drew how each of the different systems linked together based on my understanding, which was reviewed and amended by IT3 until it accurately depicted the technical ecosystem (Figure 4.3).

Following the demonstration of the wider systems infrastructure guided by IT3, I spent one hour visiting two wards to learn about the general ward environment. During this time, I unobtrusively observed different HCPs using the main clinical system on the wards. I visited the respiratory ward and gynaecology ward. The gynaecology ward was a completely paperless ward, and IT3 wanted me to compare this to the respiratory ward, which used both paper and digital records. Data was captured through handwritten notes made immediately after the observations, as I was advised by IT3 not to bring my notebook onto the wards for hygiene control. The aim of the observations was to develop an appreciation for how systems are used in their real-world clinic contexts, enabling more informed discussions during the later design of the dashboard.

[3]EMIS is an electronic patient record system used in many primary care services in the UK, such as GP practices.

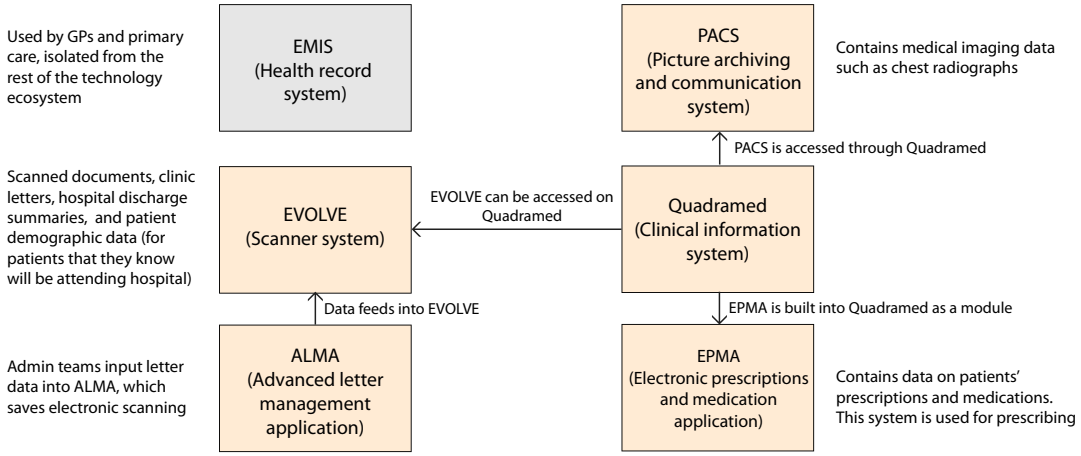


Figure 4.3: The technology ecosystem at the Hospital.

After my engagements with IT3, the next step was to explore HCPs' data needs in more detail to understand their core priorities. I conducted two 2-hour workshops with HCPs, BI, and IT at the Community Care site. H3 and IT1 were in one workshop, while in the other was H4, C9, BI1 and BI2. Two workshops were required due to the difficulty coordinating a time suitable for all participants. To manage this, I ensured there was at least one BI or IT representative present with a HCP in each workshop. It was important to include BI and IT staff to draw on their expertise about how feasible it would be to collect, and visualise, the discussed data on a dashboard.

During the workshops, HCPs were tasked with thinking about their top three data priorities, which would best support their work. They were asked to rank each priority by level of importance in relation to the timescale of delivery. For example, orange post-it notes represented *'things I would like to access right now'*, fuchsia represented *'things I would like to access in the next 2-5 years'* and blue represented *'blue-sky thinking; if I could have access to any data without limitation'*. The blue-sky thinking approach allowed HCPs to think freely about their needs without limits, ensuring they did not fixate only on the requirements that they believed were possible (which may underestimate what could be achieved). HCPs justified their data needs by discussing

the current challenges that occur without having that data for support. While the HCPs were working on this, BI and IT were tasked with assessing each of the data priorities and deciding whether the data was readily available, or if there were any barriers to accessing it (see Figure 4.4). This activity sparked thoughtful discussion between both participants groups about the challenges faced in practice and the potential role of a dashboard. After the sessions, I created a priorities document that summarised the workshops to use in the final phase of this stage (see Appendix C).

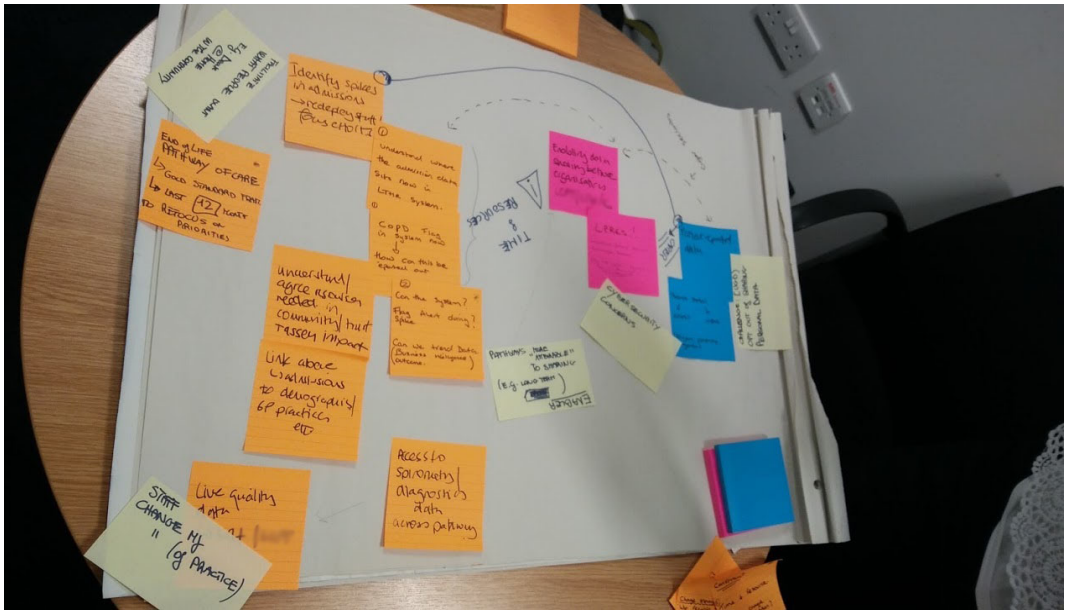


Figure 4.4: Participants' data priorities mapped onto post-it notes.

The final phase of Stage 2 involved updating the wider stakeholder team about the workshop activities. To do this, a focus group was held with BI1, H4, C7, and C9. During this focus group, it was established that the different data priorities for both organisations warranted the dashboard to have two separate views (one view for the Hospital and one view for Community Care). Within these views, the dashboard would be split into a *service view* (which observes the overall performance of their respiratory service), and a *patient view* (which shows an overview of an individual patient) (see Figure 4.5). This would allow the data needs to be individualised to each

organisation. For example, there may be data that is a priority for Community Care to access, but is not a priority for the Hospital. Therefore, splitting the views allows for the most pertinent data to each organisation to be visualised. However, we discussed the importance of having access to both organisations' view for the purpose of their collaborative work.

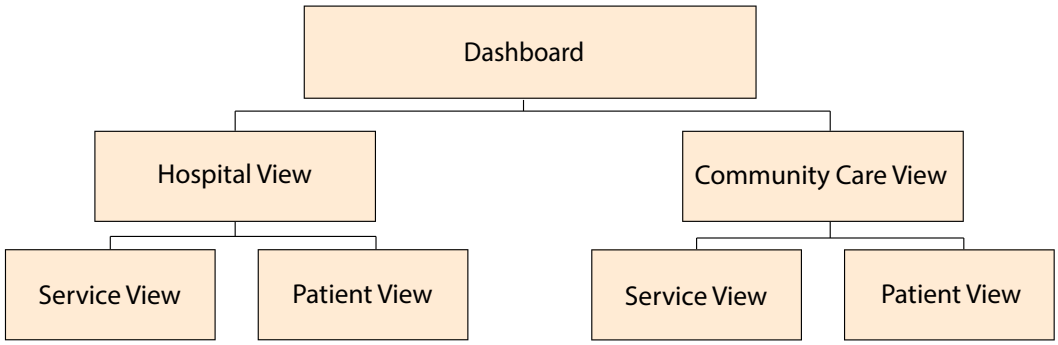


Figure 4.5: Dashboard split as proposed by participants.

The findings from this stage are presented in section 4.4.2 (pg. 96).

4.3.4 Reflections on Stage 1 and 2

The multi-stakeholder approach taken throughout the first two stages of the study allowed a number of multifaceted challenges to be uncovered. The key challenges were: (1) how a cross-organisational dashboard could implemented, managed, and maintained; (2) how the appropriate time and resources could be allocated to the project; (3) how the required data would be pulled from all systems and physical locations for collation on a dashboard; and (4) how the governance around data sharing and access would be managed. And finally, a challenge more relevant to me: (5) how this could all be addressed and achieved within the duration of a PhD.

I concluded that the above challenges meant that it would be difficult to end the design process with a fully functioning dashboard for evaluation. Instead, I opted

for the creation of a high-fidelity prototype that focused on fewer — but key — functionality that the original dashboard was designed to provide.

4.3.4.1 Moving Forward with Scenario-Based Design

I decided to proceed the study using a scenario-based design approach. Scenario-based design is centred around a set of 'scenarios', which are defined as task-driven descriptions of particular work instances (Carroll, 1995). They are use-oriented, focusing on how the system can support human activities (Carroll, 1995). Scenarios are effective for qualitatively evaluating usability, suitability, and user experience of a system (Bardram, 2000; Carroll, 1995; Dahl et al., 2010; Favela et al., 2010). This involves users completing a set of work-related tasks using the proposed system and evaluating their experiences. Scenarios have been used in previous Human-Computer Interaction (HCI) and Computer-Supported Cooperative Work (CSCW) research to evaluate healthcare systems and prototypes (Bardram, 2000; Favela et al., 2010). They are particularly effective for eliciting detailed feedback from users without deploying a fully functioning system into clinical practice (Favela et al., 2010). This inspired me to gear the design process towards creating a scenario-based prototype instead of a fully functioning dashboard.

4.3.5 Stage 3: Wireframing and Scenario Creation

The third stage focused on making paper prototypes to create tangible designs that could explore the HCPs' needs in more detail. A total of five workshops were conducted with the HCPs (H1, H3, H4, C7, C8, C9, and C11). They were tasked with

wireframing[4] the dashboard[5]. The first two sessions involved the Hospital and Community Care HCPs separately. This consisted of two sessions with each group (totalling four workshops), before uniting them in the last session (workshop five). Sessions lasted between 60 and 90 minutes. The focus for the first session was to explore the key data the dashboard should present (and how) within the different sub-views (patient and service level, see Figure 4.5). The subsequent sessions followed on from the first session, focusing on discussing the sketches and initial ideas in further detail. I describe the sessions in more detail below.

4.3.5.1 Wireframing

During the first sessions, HCPs were provided with A3 sheets of blank paper and pencils. They were asked to sketch out initial interface designs that centred around visualising their data needs (see Figure 4.6 and 4.7). The aim was not to create perfect interface designs. Rather this activity was aimed at creating tangible representations of their data needs depicted within an early interface plan. This allowed the exploration of not just data needs, but data representation and visualisation.

HCPs were asked to divide the time between sketching designs for the service overview and the patient overview respectively. They were first asked to consider what the prototype should look like when the patient and service view were first opened (i.e. demonstrating what their respective 'homepages' would look like). They were then individually asked to sketch one sub-view within both patient and service views which represented a task they believed the dashboard should support. To facilitate the sessions, I asked questions such as 'once opening the service level view of the

[4]Wireframes are technical design 'blueprints' (Marsh, 2015). Wireframing is the process of creating wireframes.

[5]Although we were creating a scenario-based prototype, myself and participants still used the term 'dashboard' to describe what we were creating, for simplicity and out of habit.

dashboard, what would be the first thing you would want to see about the service?', 'what data would be included within that?', and 'how would you want to interact with that?' After the first session, for both groups, I collated the sketches and created digital wireframes that captured the discussed concepts. These were then provided in paper format in the subsequent sessions to follow on from the first session.

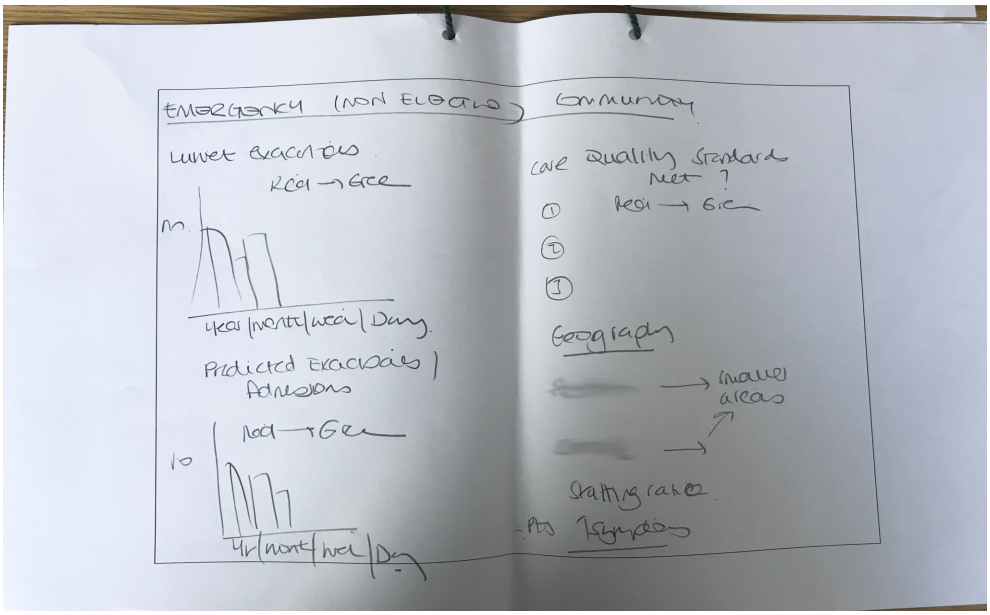


Figure 4.6: Participant H3's initial sketches of the service view.

The subsequent sessions were focused on revisiting and refining the wireframes created in the prior sessions, further exploring the ideas in more detail. Instead of expanding the designs with new ideas, I asked HCPs to focus specifically on fewer impactful tasks the dashboard should support. These tasks became known as 'scenarios'. For example, Figure 4.8 shows two panels, which would be two distinct scenarios: (1) accessing the patient's spirometry result test history; and (2) accessing the patient's hospital admissions history. I asked for HCPs' thoughts on the collated wireframes which I had produced after the first session, encouraging them to amend and discuss them. For example, for some parts of the wireframes, HCPs amended the way certain data was visualised (such as requesting to supplement tables with

graphs or changing graph types). They also refined the types of data displayed on certain views (such as removing data items they felt were not important to include on reflection: see Figure 4.8).

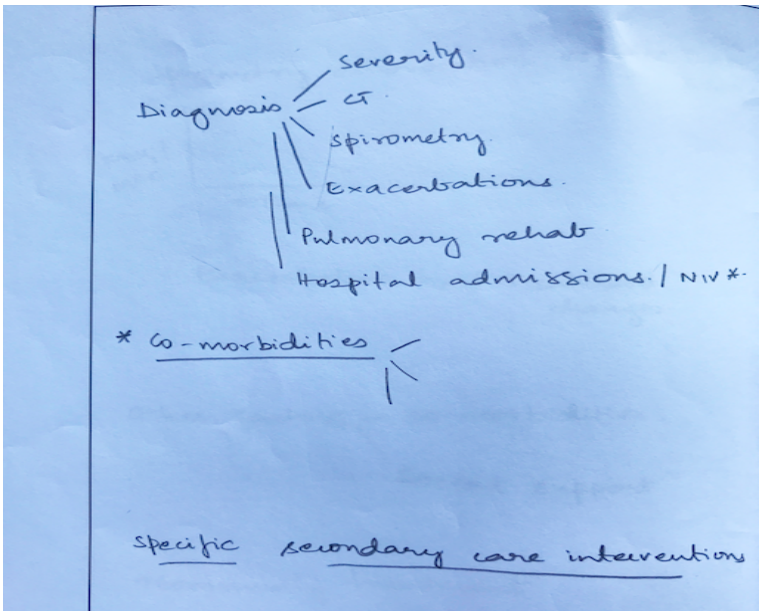


Figure 4.7: Participant H1's initial sketches of the patient view.

After each group had their second workshop (when a total of four workshops had been completed overall), I revised the wireframes a final time to reflect their suggested changes. The output of the sessions were 11 Hospital scenarios and 10 Community Care scenarios that the dashboard should support (Table 4.2). I presented the final wireframes in the joint session to stimulate discussion (workshop 5). This workshop brought together H3, C7, C8 and BI2 and lasted 30 minutes. The aim was to share the wireframes and ideas with both groups of HCPs (Hospital and Community Care) for discussion and comparison. This was an important step to allow HCPs to identify areas of shared interest across both organisations. BI2 was included in the workshop to gather their thoughts on what had been designed.

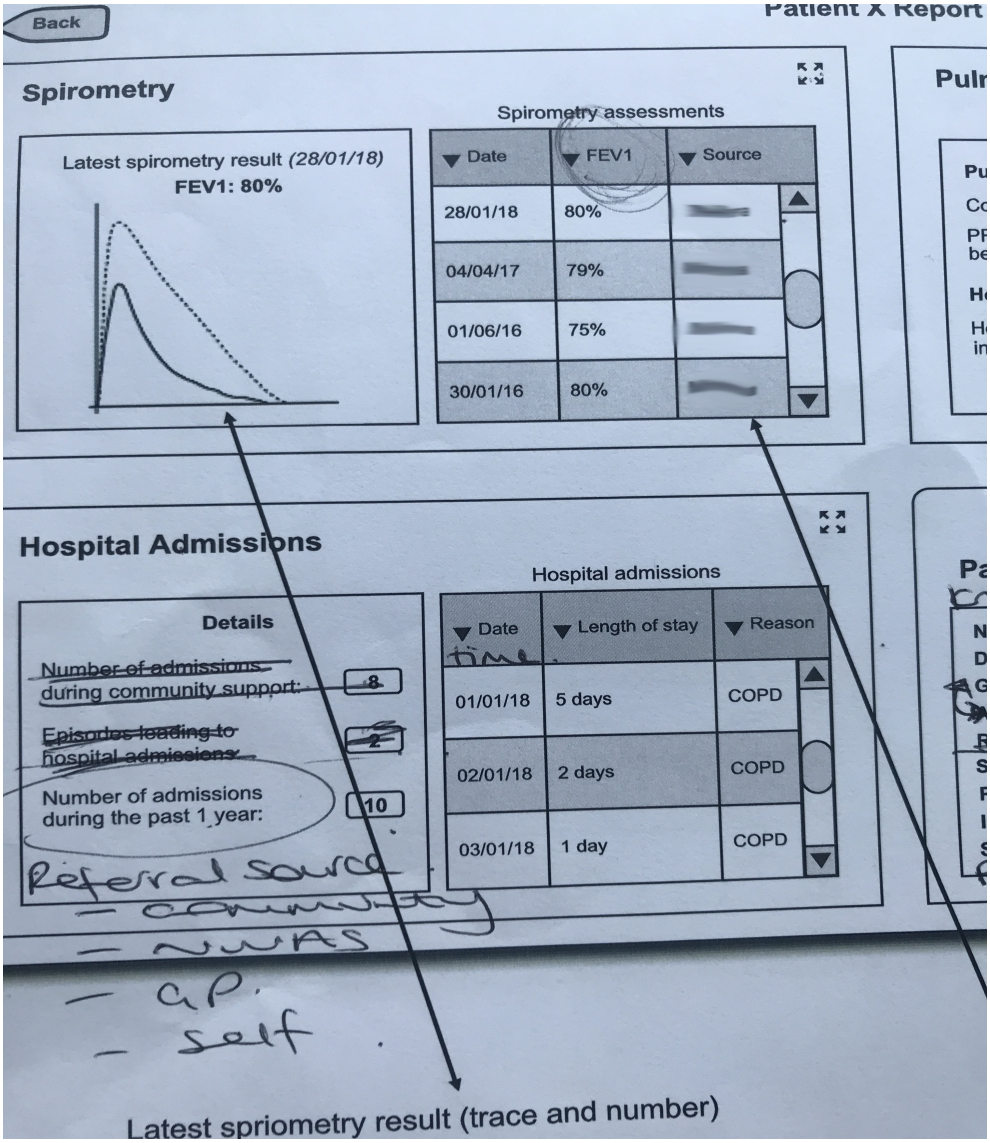


Figure 4.8: Edits to the wireframes made by participants.

Organisation	Scenario Number	Scenario Summary
Hospital	1*	View a patient's history of spirometry tests results and where each test was taken
	2*	View a patient's history of COPD specific hospital admissions
	3*	View patient-generated data around COPD symptoms and predict exacerbations based on this
	4*	View a patient's history of COPD interventions such as PR classes and smoking cessation
	5*	View a summary profile about a patient, including their medication list, comorbidities, and breathlessness score history
	6	View a patient's exacerbation history reported by the Hospital, Community Care, and their GP
	7*	View live data about COPD related hospital admissions to understand demand
	8	View a geographic heat map of current exacerbations and available HCPs in those locations
	9	View flu vaccination uptake of COPD patients across different healthcare practices
	10	View live data on exacerbations being managed by Community Care to understand demand
	11	View local environmental and air pollution data that impacts COPD symptoms
Community Care	1*	View a patient's history of spirometry tests results and where each test was taken
	2*	View a patient's history of COPD specific hospital admissions and their method of admission
	3*	View patient-generated data around COPD symptoms
	4*	View a history of COPD interventions offered to a patient, such as PR classes and intensive home support, including length of time on intervention or if the intervention was declined
	5*	View a summary profile about a patient, including medication list, available support contacts, breathlessness score history, and date their inhaler technique was checked
	6	View PR and intensive home support referral rates, including contact numbers (how many patients they reached) and type (face-to-face or phone call)
	7	View clinic referral numbers, including number of patients seen, number that did not attend, and number to follow-up
	8	View the number of diagnostic and annual spirometry tests undertaken at GP practices
	9*	View live COPD related admissions at the Hospital to understand demand
	10	View the overall number, contact numbers, contract type, and referral sources for palliative patients on their service.

Scenario numbers denoted with an asterisk * represent overlapping scenarios across the Hospital and Community Care.

Table 4.2: Scenarios from the Stage 3 wireframing sessions. All mentions of 'patients' are about COPD patients.

4.3.5.2 Shortlisting Scenarios

After the wireframing sessions, it was time to create a digital scenario-based prototype. A digital prototype would create a realistic interactive experience for the HCPs, which would be important for the evaluation. I decided to prioritise and shortlist the number of scenarios to include in the prototype (from the current list of 21 collective scenarios). Shortlisting scenarios meant that I could focus on capturing a rich and meaningful understanding of how a subset of scenarios would support HCPs' work. This compares to covering more scenarios in less detail. I aimed for each evaluation session to last for one hour (which was the typical time on average I was able to meet HCPs for). Therefore I decided to limit the number of scenarios to five, which would allow at least ten minutes to discuss each one.

To decide which scenarios to shortlist, I thematically analysed the wireframing workshop transcripts to determine which scenarios featured most prominently in discussion. From this I identified the types of discussions about each scenario and how often the scenario was referred to. It would have been ideal to conduct this shortlisting activity with HCPs, but due to their busy schedules I had to forgo this activity myself. However, I had enough knowledge to make an informed judgement about which scenarios to shortlist from being embedded in the process. Additionally, I aimed to prioritise scenarios which overlapped between both the Hospital and Community Care (i.e. scenarios which they both discussed). For example, scenario number one (accessing a patient's spirometry test results) listed under both the Hospital and Community Care in Table 4.2. Choosing overlapping scenarios would mean all HCPs would be presented with the same scenarios in the evaluation. This would aid data analysis by comparing and contrasting the feedback on the same scenarios.

After I had chosen the five scenarios to shortlist, I wanted to validate my choices with the HCPs before moving forward with the digital prototype. I met with one HCP from both organisations (H4 and C7) to discuss the scenarios and approve the final versions of the wireframes from Stage 3 (which the upcoming digital prototype would

be based upon). I used these discussions to create user stories[6] about each scenario. Creating user stories helped to gain a clear, structured focus of why each scenario was important to the HCPs. This would help to create the discussion prompts for the evaluation in Stage 4. The five scenarios shortlisted and validated for inclusion in the digital prototype are in Table 4.3.

Scenario Number	Scenario Name	Scenario Description
1	Respiratory Ward Overview	An overview of COPD in-patients at the Hospital, including their ward location, length of stay, and their number of previous COPD related admissions. The overview is split by patients who are in hospital with COPD as their primary admission reason, and those in hospital with COPD as their secondary admission reason
2	Admissions and Exacerbation Reports	Live reports of COPD related hospital admissions and exacerbations on a population level. The exacerbation data is reported by the Hospital, Community Care, and GP practices in the locality
3	Patient-Generated Data Overview	Overview of patient-generated data about COPD symptoms recorded by patients via a hypothetical mobile app. Clicking on an individual patient's reports opens up their individual data entries which can be viewed as a time series
4	Example Patient's Exacerbation History	A view of a patient's history of clinically reported exacerbations, reported by the Hospital, Community Car, and the patient's GP practice
5	Example Patient's Spirometry Results	A view of a patient's spirometry test result history, reported by Hospital, Community Care, and the patient's GP

Table 4.3: The five shortlisted scenarios to include in the digital prototype.

4.3.5.3 Creating the Digital Scenario-Based Prototype

After creating the user stories based on discussions with the HCPs, I worked with a research associate, Dr Adrian Gradinar, who developed the scenario-based prototype base from the designs. The prototype was built as an Angular web app. Adrian and I worked iteratively during the development phase: I provided him with the annotated

[6]User stories capture users' goals relating to carrying out a task using a system (Cohn, 2004).

wireframes and specifications for the development (Appendix D). I also shared the user stories with Adrian to ensure a shared understanding of the value that each scenario should deliver. I created a series of dummy datasets, with advice from a biostatistician researcher, Dr Olatunji Johnson. These were used to populate the prototype so it could support interaction during the evaluation with the HCPs (Appendix E).

After the first version of the prototype had been developed, I met individually with a group of HCPs for feedback (H2, H3, H4, C7, C8 and C9). This was an important step to ensure that the designs translated well across mediums (paper to digital). I brought a laptop to the meetings to demonstrate the prototype, and asked participants to comment on each scenario in its first-version form. I emphasised that, at this stage, the feedback should be focused on any slight alterations to the interface, wording of labels, or dummy data, rather than the addition or subtraction of any features. Following the feedback from the HCPs, the prototype was minorly amended and finalised for evaluation (Appendix H shows each finalised scenario).

The findings from this stage are presented in section 4.4.3. (pg. 102).

4.3.6 Stage 4: Evaluation

The final stage was the evaluation of the prototype with HCPs. The aim was to collect feedback about the prototype. This was facilitated by walking through each scenario and exploring how HCPs believed (or did not) the prototype could support their decision-making about COPD care. The evaluation would provide HCPs with the ability to interact with the prototype as if it were a real system. This would stimulate meaningful and realistic discussions compared to utilising paper prototypes.

Evaluations were held at quiet rooms at both clinical sites, each lasting between 60 and 90 minutes. They were conducted one-to-one between myself and each HCP (11 in total, detailed in Table 4.1). The HCP was first asked to answer basic demographic information (age, gender, years in current role, and experience in years using clinical systems) to provide additional context for data analysis. I provided

participants with a laptop with the prototype loaded, and asked them to navigate through each scenario sequentially (Figure 4.9).

Before moving to the next scenario, they were asked rate (on a 7-point Likert scale) how realistic they perceived the scenario to be ('does this scenario respond in a way that you would expect when using a system to complete this task?') and its relevance to their job ('is this scenario something you would use in your role?)[7]. Understanding the HCPs' perceptions on realism and relevance would complement the analysis of the scenario discussions. For example, a high rating would provide some confidence that the HCPs could engage with the prototype meaningfully (i.e. it supported their mental model of that task and they could envisage how the scenario could be used to support their work). Moreover, I was aware that each scenario may have different levels of relevance for each HCPs and this was important to consider when analysing the feedback[8].

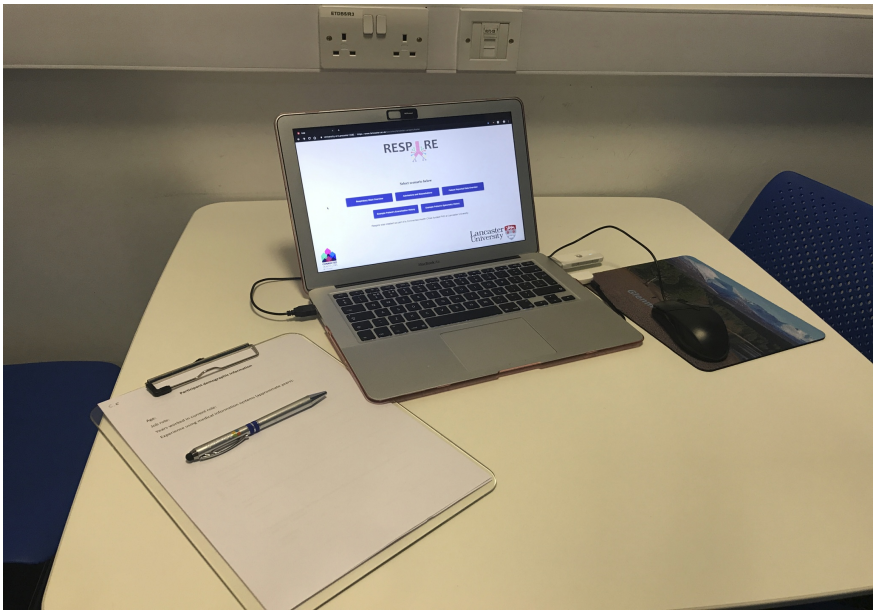
When walking through each scenario, HCPs were asked to interact with the prototype freely by exploring different tabs, reviewing the visualisations, and examining the data. They were encouraged to think aloud[9] while exploring each scenario (Fonteyn et al., 1993). I prompted discussion by asking open-ended questions such as 'do you feel that the data presented to you in this format could influence your decision-making?', 'are there any challenges that you could envisage when using this scenario to undertake a task?' and 'who do you think needs to be involved in the collection and maintenance of this data to ensure it is useful?'

To conclude the evaluation, I asked the HCPs to complete two short question-

[7] I referred to this as the Realism and Relevance questionnaire.

[8] Shortlisting five scenarios from the total of 21 that were generated in Stage 3 meant that some scenarios would be more relevant to some HCPs than others.

[9] This involves participants verbally sharing their thoughts out loud while undertaking a task.



The prototype's homepage is loaded on the laptop screen, with buttons to select a specific scenario.

Figure 4.9: The evaluation set up at one of the clinical sites.

naires. The first asked them to rank the usefulness of the scenario from one to five (with one being the most useful to them in their role)[10]. The second questionnaire was a Technology Acceptance Model (TAM) questionnaire (Davis et al., 1989; Hornbæk and Hertzum, 2017) which is intended to predict if a user will accept a new technology[11]. TAM was primarily designed as a theoretical tool to quantifiably measure user acceptance of a technology in information systems research. However, my intention was not to use TAM as a form of theoretical predictor that the prototype would be accepted by the HCPs in practice. Instead, the intention was to use the data generated from the TAM questionnaire to supplement the richer qualitative insights from the

[10] I called this the Usefulness questionnaire.

[11] Technology acceptance can be defined as 'an individual's psychological state with regard to his or her voluntary or intended use of a particular technology' (Hendrick et al., 1984; Hu et al., 1999).

evaluation. The TAM data would provide an indicator about how the experience of the prototype mapped to theoretical components central to technology acceptance (which are 'perceived usefulness' and 'perceived ease of use' in standard TAM by Davis et al. (1989)). TAM has been used this way in HCI and CSCW research by Knowles and Hanson (2018a) and Favela et al. (2010).

The TAM questionnaire was created in collaboration with a Professor of Respiratory Medicine, Professor Mike Pearson[12], to ensure the questions were clinically meaningful and relevant to healthcare contexts (see Appendix G). I used the TAM questionnaire provided in Davis and Venkatesh (1995) as an initial starting point[13] to adapt core questions which were grounded in previous TAM literature. As I revised the questions to make them specific to the prototype and healthcare context (which Holden and Karsh (2010) and Bardram (2018) encouraged when using TAM in healthcare research), I iteratively received feedback from Professor Pearson to ensure the questions were applicable to clinical decision-making.

The findings from this stage are presented in sections 4.4.5 (pg. 110) and 4.4.6 (pg. 113).

4.4 Findings

This section presents the findings from all stages of the study (Stage 1: Scoping the Design Space, Stage 2: Priorities and Implementation Challenges, Stage 3: Wireframing and Scenario Creation, and Stage 4: Evaluation). Findings from each stage have been separated into distinct sections.

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[12] Professor Mike Pearson was independent from the study and both NHS organisations.

[13] Davis and Venkatesh (1995) used TAM to evaluate a word processing software.

4.4.1 Stage 1 Findings: Scoping the Design Space

The following sections describe the findings from Stage 1, involving three one-to-one interviews with HCPs (H3, H4, C6), a two-hour interview with IT staff (IT, IT2), and focus group with HCPs (H3 and H4) and BI staff (BI1, BI2, BI3). Five themes arose from the thematic analysis, which were refined into two key themes: (1) 'lack of data for daily decision-making' and (2) 'lack of data for strategic planning'. Both key themes are discussed in detail below.

4.4.1.1 Lack of Data for Daily Decision-Making

HCPs were asked to discuss areas where they felt a dashboard would alleviate some of the challenges they faced in their everyday work. They highlighted the difficultly of making informed decisions about the care of individual patients, as data about their full care journey is captured and stored in different digital systems and formats across care organisations (such paper notes, digital notes, and spreadsheets). The problem was further intensified by the fact that they did not have access to each system where digital data was held, which made it difficult for them to decide the next steps to take when planning care for a patient. H3 described care services as *"fragmented"*, whereas having access to *"a real patient story"* would allow for HCPs to *"compare and contrast [information about the patient] in order to make a case for change, and lead [their care] with that change."* Though BI1 agreed that *"systems don't necessarily talk that well together"*, they justified the use of multiple systems as providing the technical ability to *"capture more detail"* through the use of systems that are specific to a certain aspect of patient care. The overall challenge in accessing data about a patient's care was summarised by BI2 as follows: *"the key thing is there's the Hospital and the Community [Care], and patients will move to one place to another. So when they're at the Hospital, I guess it's the systems the Hospital are using and then when they're in Community [Care] it's the IT systems we use"*. The fact that patient data is held across different systems, organisations, and formats, created difficulty for HCPs to fully inform themselves about a patient's care journey, particularly when different

care organisations are involved in that patient journey.

When probing HCPs further to understand what processes they undertake to obtain some of the data that they need, they described having to call or write to other HCPs from *"acute services, community services, [and] general practice"* (H3) to request the required data. For example, C6 described having to phone the emergency department of the Hospital to understand if any Community Care patients were admitted to hospital, and that *"[it was] very difficult to either get through or speak to anyone who knew what was happening."* Likewise, H4 discussed needing to *"physically ask the GP to fax [spirometry test results]"* and how they felt frustrated that they could not *"see the investigation [test result] on my [computer] screen"*. In some cases, C6 noted that a lack of data sharing caused HCPs to spend time on redundant tasks: *"the Community [Care] team would have referrals sent in, and when they went to ring or visit the patient, they were already in the Emergency Department, so knowing they were in the Emergency Department would save wasted activity."* BI1 explained that the lack of data sharing is due to *"information governance agreements"* which need to be established between collaborating organisations to share data about their patients[14]. This meant that although HCPs could share data about their mutual patient verbally and through letters, it could not be digitally shared through their IT systems.

4.4.1.2 Lack of Data for Strategic Planning

The lack of access to data useful for the strategic planning of services and resources was another challenge that HCPs faced in practice. They were concerned that they were working under *"unpredictable"* (H3) conditions that are not supported by any *"live data"* (H3). One key area discussed was the number of hospital admissions

[14]In this case, the Hospital and Community Care needed agreed policies and processes around data sharing for the purposes of direct patient care. Different healthcare organisations may have different approaches for sharing patient data across collaborating organisations.

relating to COPD, particularly relating to sudden spikes, which makes their services *"vulnerable"* (H3). H3 discussed that it is commonly understood that more COPD admissions occur in winter months *"because patients tend to flare up with their COPD with viral infections and stuff like that"*, but sudden spikes within those months are challenging to deal with and *"we [HCPs] need to understand what is going on"* (H4) to effectively deal with increased service use. One method that was highlighted as a way to deal with increased service use is to *"allocate our resources slightly differently to be able to deal with that [spikes]"* (H3), for example, through allocating *"a community nurse or somebody in the hospital to go around and look at all these patients"* (H3). As such, accessing service level data could allow HCPs and service managers to better adapt to increases in service usage.

It was further discussed by the wider stakeholder group that insights into what causes spikes in admissions and referrals could potentially be identified if data was linked across care organisations. Understanding *"what is resulting in them [patients] coming into hospital in the first place"* (H4) could act as a first step in working towards decreasing admission and referral rates. For example, BI2 highlighted a specific instance of this: *"if you suddenly saw an increase in activity from a particular GP practice and you could see there's a spike [in referrals for diagnosis or admissions], then you could go and do some further investigations and there might be that there's a locum in for 6 months"* and that *"it's being able to visualise it and easily see where the connections might be"*. The linking of data in this way was thought to be a possibility to not only improve the Hospital and Community Care COPD services, but service usage across all COPD care organisations including GP practices.

4.4.2 Stage 2 Findings: Priorities and Implementation Challenges

The following sections detail the findings from Stage 2, involving an observation of the clinical systems (IT3), two workshops with HCPs (H3, H4, C9), BI (BI1, BI2), and IT staff (IT1), and a focus group updating the stakeholder team jointly (BI1, H4, C7, C9). Eight themes arose from the thematic analysis, which were refined into five main

themes: (1) 'integrating new systems into workflow'; (2) 'need for quality data'; (3) 'need for meaningful data'; (4) 'the future of patient-generated data'; and (5) 'digitally supporting data needs'. These five main themes are described in detail below.

4.4.2.1 Integrating New Systems into Workflow

A challenge to integrating a new piece of software for use by the Hospital and Community Care HCPs was related to training staff. Training was highlighted by IT3 as a challenge for HCPs due to the limited time that they could dedicate away from clinical practice to be trained on new systems. It was noted that staff tend to be trained *"gradually"* (IT3) at different time periods to help avoid many staff from being absent from clinical practice at once. However, this gradual approach meant that there were often staff, and locum staff, that were not trained on the system that they were using. In addition to the gradual approach meaning that some staff were not trained, IT3 reflected on their experiences of staff believing that their, often fallible, intuition was sufficient enough to mean that they did not require official training on systems. This led to two challenges: data entry errors and inefficient task execution. Data entry errors were not always immediately flagged as some systems did not have certain validation checks (e.g. the HCP may use the wrong prescription units or amounts, and the request would get sent back to them to be re-written, causing delays). Inefficient task execution referred to HCPs not learning the most efficient way to undertake a task on the system, and would therefore carry out a task using a path that they have taught themselves, which may be more time-consuming (e.g. ordering a combination of medications for a COPD patient individually, when the combination is available to order as a set on the system). In some cases, not being trained on systems led to HCPs not knowing about certain functionality that the system can provide, which meant that HCPs were not aware of shortcuts or functionality that could save time.

In addition to being trained on how to use the system, it was highlighted that there would need to be protocols established for responding to the data visualised on the dashboard. When implementing a dashboard that indicates, or forecasts, an

increase in service usage, it was acknowledged that there must be procedures put in place to enable appropriate (re)action to those indications. For example, H3 described the need for *"agreements with other Trusts about how we respond to these spikes in admissions"* which would be *"complex"* as they would need to discuss how they *"re-deploy staff"* and other resources in response to what the data suggests. This was seen as a necessary step if the dashboard were to visualise admissions in real time, as without arrangements around resources, HCPs would simply have to continue responding to admissions in the same way which they did before using the dashboard. Without these agreed arrangements (e.g. redeployment of staff), services would not become more *"proactive"* (BI2, H3) as a result of using the dashboard, which was seen as counterproductive to what the dashboard aimed to deliver.

To support building a dashboard that collates data that HCPs need, it was acknowledged that some paper data would need to be collected digitally for use on the dashboard, which would create *"some change in the way we [HCPs] work"* (H3). The organisational change from recording on paper to recording data digitally was another challenge area identified in discussions with participants. It was highlighted that one of the main organisational challenges would be *"transforming people's ideas about how they put information into systems"* (H3) when shifting from paper to digital, as there *"there may be some resistance to that"* (H3) due to the way it changes how work is carried out. This resonated with findings from the ward observation, in which a HCP highlighted that their team were initially against the digitisation of prescription services due to change in work flow and their perceived lack of technical competence to use a new system. However, IT2 noted that there is a gradual transition from paper records to digital across care services in light of the UK government's push for a paperless healthcare system (Honeyman et al., 2016), and this may act as a motivator for HCPs to persevere with digital data input. The technical challenge associated with transitioning from paper to digital, highlighted by IT2, related to how adding additional data into their existing systems would *"change the way that the current data is held in there"*. Changing the way that data is held in the current system would take *"time and constraint"* (IT2) to adapt the system, which was highlighted as being technically

feasible but challenging to carry out.

4.4.2.2 Need for Quality Data

The reliability and trustworthiness of some data that would be used for the dashboard was identified as a challenge area. This particular point related to the diagnosis of COPD through spirometry tests. The wider stakeholder group acknowledged that there were some *"issues around diagnosis [of COPD]"* (H3) which meant that some patients were being improperly diagnosed with COPD (i.e. misdiagnosed) and referred into clinics held at the Hospital and Community Care. The misdiagnosis of patients created an increase in service usage and *"puts the patient on the pathway that they might not need to be on"* (BI2) which can cause additional work for HCPs and undue stress for the patients. For H4, misdiagnosis occurred for two reasons: (1) improper investigation of symptoms and (2) HCPs being poorly trained to undertake spirometry tests. For improper investigation of symptoms, H4 and H3 were concerned that some HCPs believe *"they've [the patient] smoked for a bit, they've been a bit breathless, this could be COPD"* (H4) and then proceed to diagnose the patient with COPD without taking a spirometry reading. For poor spirometry training, H4 and the wider stakeholder group agreed *"the quality of spirometry depends on where the patient has attended that test"* (BI2), as HCPs in primary care organisations may not be properly trained in delivering the tests. As a result of the quality concerns, H3 noted that they *"can't really be sure that it [the diagnosis] is correct"*, and would have to re-do the tests themselves. H4 expressed frustration at this, mentioning that re-doing spirometry tests to ensure they are accurate caused *"duplication for the patient"* and that they feel they are *"forgetting the patient in the middle of doing all these things"*.

Although there were quality concerns about spirometry tests, and the dashboard would *"only [be] as good as the data you put into it"* (H3), HCPs highlighted having access to this data as one of their top priorities for the dashboard. H4 remarked that this would put an end to needing to *"beg, borrow, and ask somebody"* for their patients' spirometry test results. There was an acknowledgement that viewing this data

could also allow services to identify *"the number of inappropriate referrals"* (BI2) which would make *"a massive difference"* (BI2) in being *"able to track it back"* (BI2) and target those services with support and training to *"ensure that there is accurate spirometry across the entire patch"* (H3). However, there was an acknowledgement from BI staff that creating visibility around the individual practices which make incorrect referrals could be considered *"political"* (BI2), and as such, there would need to be a thorough consideration of the granularity of the listed source of the spirometry test alongside *"who has visibility of that"* (BI2).

4.4.2.3 Need for Meaningful Data

The process of obtaining *"meaningful"* (H3, IT2) data was highlighted as a challenge when using the current systems. HCPs illustrated this point by discussing the process they undertook to access a list of patients who are in hospital with a COPD related admission, which they carried out daily. H3 described having to log onto the main Hospital system and would *"bring up a list of patients who have got this flag [as having COPD] but it won't say whether the particular admission is because of their COPD"* or a *"nose bleed"*. For the HCPs, being able to access this list easily and meaningfully was a priority. However, they found they had to either *"ring the ward"* (H3) or physically click into each individual patient profile on the list to clarify what their admission was, which H3 stated was *"a waste of time"* and they did not *"have the capacity to do this for every COPD patient"*. Currently, the main system makes use of 'data flags' on a marker system, which are tags that link patients to certain conditions or codes (such as a 'Do Not Resuscitate' Code). Patients that have been diagnosed with COPD (whether correctly or incorrectly) will have a COPD flag associated with their profile, as a way to easily link them to different system functionality. IT2 sympathised with the concern, and stated that more meaningful flags would differentiate between patients that are in Hospital for a *"COPD patient problem"* and those where they are in hospital for another reason, such as *"a broken leg"*, so that staff members can prioritise which patients they need to attend to.

4.4.2.4 The Future of Patient-Generated Data

As a form of blue-sky thinking, HCPs discussed their desire for patients to record their own health data at home. They were especially excited at the prospect of being able to view patient-generated data around symptoms *"using an app"* (H3) or otherwise *"electronically"* (H3) to help in identifying patients that are struggling to cope as *"we [HCPs] know patients do delay and put off seeing their doctor in case they go to hospital"* (H3) and *"see if there's particular flare ups in particular areas on a population level"* (H3). The reason that this was not seen as something immediately feasible was because, as H3 discussed, they believed they had a *"long way to go to be able to get patients to record the data"* because *"the cohort of patients that we deal with are generally not very electronically savvy"* but they believed that this will *"change"* as older adults become more comfortable with technology. However, H3 highlighted it would be important to first understand *"how can we [HCPs] practically interact with it [patient-generated data]"* for patient care.

The type of data they discussed as being most useful was *"subjective reports of symptoms"* (H3) as *"two people with the same spirometry [history] might show quite different levels of symptoms"* (C9). While discussing how patients currently self-manage their symptoms, C9 reflected on patients' use of a paper self-management booklet currently used at their organisation, citing its *"poor"* adoption as there are *"lots of colours and lots of ticks, and people just look at them and go I'll never be able to do that"*. However, C9 believed that a simpler system could have a *"better response"* that would give patients *"autonomy and the empowerment to manage their condition"*. In response to this priority being highlighted, IT2 stated that the sharing of patient-generated data would require a *"patient portal"* being built, which is feasible, but is not currently supported in their systems. In addition to building a patient portal would be the organisation of *"patients giving permission"* (IT2) for their data to be shared, which would need to be arranged from an information governance standpoint. One of IT2's concerns around building a patient portal to share data was about potential cyberattacks, as a portal could become a gateway for exploitation.

4.4.2.5 Digitally Supporting Data Needs

One of the most prominent challenges for creating the dashboard was around the lack of flexibility that the current systems offer, meaning it would be challenging for systems to be adapted to start recording data required for the dashboard. BI2 described the main system at the Hospital as being *"a very old system"*, and that they hold a long contract meaning *"it's essentially is as it is"* and *"our hands are kind of tied in terms of what we can do"*. This would make it difficult to incorporate all of the HCPs' data needs, as the design of the system would become bound to the possibilities within current systems (unless systems were altered and updated, which would require lots of *"time and resource"* (IT2)). For example, C9 discussed using a spreadsheet as a workaround to capture the number of assessments, referrals and the outcomes of pulmonary rehabilitation, which was very *"manual"* and *"doesn't work properly"*. In response to this, BI2 noted that this data was *"not really something at the moment that current system are able to record"* but if it were, visualising it would be *"dead easy"* (BI2). The use of workarounds was justified by BI1, who stated: *"having a system across the Trust that fulfils everyone's demand in services that operate very differently is very challenging, and this is why you have these things like spreadsheets and recording things in this way because there's no alternative bespoke system . . . it's basically because we can't have the flexibility to have it in the main system."*

4.4.3 Stage 3 Findings: Wireframing and Scenario Creation

The sections below discuss the key findings arising from the five workshops, four of which were wireframing and scenario creation activities with the HCPs, and the fifth workshop bringing HCPs together and BI1 for feedback. The workshops aimed to uncover and visualise data needs. The findings from this stage relate to three types of information needs (resulting in three key themes): (1) 'understanding patient severity'; (2) 'understanding quality of life'; and (3) 'understanding demand'. The three themes are discussed in detail below.

4.4.3.1 Understanding Patient Severity

Understanding the severity of a patient's condition was a central discussion point which dominated the wireframing sessions with both the Hospital and Community Care. Hospital HCPs were keen to discuss scenarios that would help them to better understand a patient's condition when they were first admitted to hospital, such as knowing *"the number of admissions they've had that are COPD related"* (H1), *"how many exacerbations they've had, when those have been"* (H3), *"who's managing the exacerbations [in terms of the GP, Community Care, or the Hospital]"*, and *"have they ever been on non-invasive ventilation*[15] *before"* (H4) as that will help HCPs understand *"the severity"* (H4) of the patient. Understanding the severity of the patient in a way which *"could be viewed by everyone who's looking after the patient"* (H3) would help HCPs to collaboratively decide the next steps in the patients' management. For example, they might look at the patient's exacerbation history and then ask:

> *"This patient has had two to three admissions needing non-invasive ventilation, have you thought about domiciliary ventilation*[16]*? Or, they've not done pulmonary rehabilitation in over a year - or over a few years - could they do that?"* (H3)

H3 discussed that seeing this information in *"some kind of graphical representation"* over time could help support the easy identification of trends, and how the patient's condition may have changed, as *"when you see patients from admission to admission you might not necessarily join everything together"* (H3) so having access to a cohesive story of the patient's condition history *"would be helpful"* (H3) for decision-making. Adding to this, H4 described the importance that exacerbation and data on a patient's past exacerbations is *"merged"* (H4) with data from *"whoever they've [the*

[15] Non-invasive ventilation is a method of providing ventilation support to a patient, usually through a mask worn over their mouth and nose.

[16] Domiciliary ventilation is support that the patient can use at home.

patient] met in their pathway" (H3) so that it provides a true inclusive picture of their condition and experience. This would directly support their work, in contrast to their current method of *"literally look[ing] through the letters [from the GP and Community Care]"* (H4) and *"reading in between the lines"* (H4) to try and piece together the patient's history.

For Community Care HCPs, accessing COPD hospital admission data for each patient was *"definitely needed"* (C11) to better understand the individual patient's care journey. Knowing the patient's exacerbation history and when they have had *"acute medication"* (C7) was *"really lacking for us in Community Care, and we really like the idea of being able to see [that]"* in a shared Community Care and Hospital *"view"* (C7). This sharing of exacerbation history data was seen as crucial to supporting patients and the collaborative work of both services as they are *"trying to get away from the 'Hospital' and 'Community Care' and make it more joined"* (H3).

It was further highlighted that collating exacerbation data from the Hospital, Community Care, and GP practices would be viewable *"in an ideal world"* (C9) to understand the severity of the patient, but to also discover potential patients whose care could be managed by a specific, more appropriate, service. For example, viewing a patient's exacerbation data which demonstrated many GP visits could allow Community Care to be *"more proactive around our management [of that patient] and making sure patients aren't missed by the [Community Care] service"*. This type of data could also facilitate support to other HCPs that offer care to the patient, as explained by C7:

> *"If patients have had three admissions by the GP, and they weren't known to us, do we need to do some education around that [GP] practice around what's available [service wise] in Community Care [for COPD patients]?"*

Being able to easily access and compare a patient's annual spirometry test results in *"chronological order"* (C7) was also seen as a useful way to understand condition severity. Particularly, knowing if the patient has had a diagnostic spirometry test, which forms one of the pillars for ensuring diagnosis has been carried out *"accurately"*

(C11) in accordance with clinical guidelines[17]. This referred back to the concerns that HCPs had that some patients they encounter have not been properly diagnosed. Having access to a collated list of results *"per patient as a comparable"* (C7) was discussed as being useful for understanding how the patient's lung function has improved or deteriorated over time (particularly in context of assessing how interventions, medication, and management techniques may have helped). Alongside having results in comparable formats, it was highlighted that HCPs tend to have access to only the numerical results of the test, which does not give adequate reassurance of the test's quality[18]. C9 and C11 shared the ways in which the spirometry trace can provide additional meaning to spirometry test results:

> *"It's the shape basically, it's the shape of the curve, it will tell you potentially a bit more about their airways. We generally just have the numbers but you look at it together, that would be useful."* (C9)

> *"I like the idea that you can actually see the trace as well ... because you can get a good idea of the technique and how they actually performed, it tells you a lot of information really"* (C11)

Having complete information about a patient's exacerbations (recorded by all healthcare services), followed by a complete history of spirometry results (a result which demonstrates both the numerical results and trace results) was seen as an effective way to better understand the severity of the patient. Completeness of information was raised as essential for capturing a true understanding of patients' condition severity.

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[17]According to National Institute for Health and Care Excellence (2010b), a spirometry test should be undertaken as part of COPD diagnosis.

[18]Spirometry test results are usually made up of numerical results about lung function performance and a graphical depiction of this as a trace.

4.4.3.2 Understanding Quality of Life

An important area discussed with HCPs was related to understanding patients' quality of life, specifically their perspective on their condition and how they are self-managing. This was particularly relevant to patients that are reaching the end stages of their life or those who are acutely unwell. It was discussed that at the Hospital, quality of life information is *"sometimes"* (H4) discussed in clinics, however *"it's physically not possible to address it every time in clinic"* (H4) with every patient due to the time allocated to clinics and the number of topics the HCP must cover with each patient. However, patients' quality of life was something that H4 was *"very conscious about"* and H3 thought was *"a very useful perspective"* for helping patients manage their condition. In addition to using this information to help patients to manage their condition, this information was thought to help HCPs have more constructive discussions with patients to help manage any *"unrealistic expectations"* (H4) about the patient's future based on, for example, the prescription of a new medication. H4 discussed that some patients may believe *"everything will get back to how they were before"* after new interventions, which is not always possible with acutely unwell patients. One method discussed as being able to support this understanding around patient quality of life was through the patient tracking a *"semi-objective measure of quality of life"* (H3) over time that the HCP could discuss with the patient in clinic.

It was also raised that accessing patient-generated data about COPD symptoms for *"capturing exacerbations and deterioration earlier"* would be useful to help patients to *"avoid potential hospital admissions and potential deterioration"* (C7). This concept was of interest to both the Hospital and Community Care HCPs. C7 raised that patients tracking their own symptoms can help them to become better *"aware of their symptoms"* as patients often only became aware of their symptoms once *"things are getting worse"*. It was further highlighted that patients recording data about their symptoms could aid with their self-management, and could be supported by HCPs as *"we can go back and look at that"* (C9) patient-generated data if a patient called the Community Service with concerns. Whereas H3 believed there was additional

potential for patients *"adding their own data particularly related to symptoms"* which would be *"really powerful data"* that could be used for *"predicting exacerbations in a totally different way that's ever been done before"* using predictive modelling, which they believed would benefit on a patient level and also population level.

4.4.3.3 Understanding Demand

Understanding and predicting the demand on the Hospital and Community Care services was also discussed as an effective way to adapt resources, but additionally, to ensure that patients are being signposted to services effectively. HCPs agreed that seeing the COPD hospital admission rate at the Hospital on a *"day by day"* (C7) basis would be useful as a way to understand the number of acute exacerbations that are leading to hospital admissions. In addition to hospital admissions data, H3 described the desire to view the *"number of patients that have been seen over a particular time [for exacerbations]"* (H3) across all services, including the number of patients which have been seen by Community Care and GP services *"so that we can see when the dips, troughs, and the peaks are"* (H3). Community Care HCPs also believed this data was important, as seeing *"the number of patients accessing their GP [service] but not our service is really useful"* (C8) in understanding *"how many patients we're missing"* (C7) and could divert to Community Care services to manage demand and provision specialised care.

Furthermore, H1 and H3 highlighted that it could be useful to know if exacerbations were either infective or non-infective, as infective exacerbation data could be mapped to *"environmental data, prevalence of flu as well, especially in the winter months"* (H3) to help forecast service usage as *"in flu season, we see a huge surge in admissions and exacerbations"* (H3). However, H3 pointed out that the clinical method currently used to differentiate between an infective and non-infective exacerbations are not particularly effective, and so understanding this distinction may be blue-sky thinking. At present, H3 described that HCPs often have to *"ask patients if they cough up phlegm, and if its changed colour, and if it has, we deem it as infective*

and give them antibiotics" as sputum culture test results are not always immediately available (and such tests are not usually undertaken at GP practice level). Therefore, being able to distinguish between infective and non-infective exacerbations was seen as something which held more exploratory potential in better understanding patterns of exacerbations, and how these may relate to service demand.

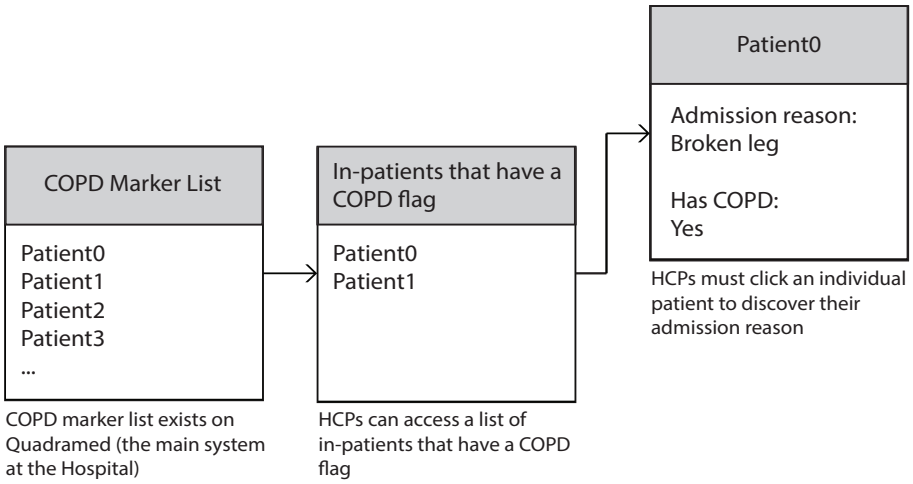


Figure 4.10: A conceptual representation of the Hospital marker system and how an admission reason is determined.

Understanding day to day service demand was also discussed as being an effective way to prioritise immediate work. Particularly, Hospital HCPs discussed needing to differentiate between admissions that are COPD related or admissions which relate to patients that have a diagnosis of COPD. This related back to the ineffective marker system that highlighted when COPD patients were in hospital, without explicitly specifying the admission reason. H3 described that this was an area that*"we really struggle with at the moment"* as the HCPs need to *"address them [patients who have come in with a COPD related admission] first"* but the process to differentiate them from unrelated admissions was laborious. For H1 and H2, being able to distinguish between admission reasons was thought to save time and allow HCPs to *"direct your resources and time to the people who need us from a COPD exacerbation point of view"* (H2)

and currently they had to make *"our own list"* on paper of patients that were showing up on the COPD list as in hospital, but not having a COPD related admission, to then remove the flag from them (which removes them from the in-patient list, but not the original marker list, Figure 4.10). Whereas Community Care HCPs described accessing the same marker system to *"look at discharge summaries"* to find out which patients they should offer follow up care to, and having to undergo the same process for understanding COPD in-patient's admission reason.

4.4.4 Recap on Scenarios

To follow the findings presented from Stage 4 (11 interviews evaluating the prototype with HCPs) in sections 4.4.5 and 4.4.6, it is important to be reminded of the five scenarios that were involved in the evaluation. These have been described in Table 4.3 (pg. 89), and the interfaces presented to HCPs on the digital prototype are shown in Appendix H (pg. 397 onwards). However, they are also summarised below:

- **Scenario 1** provides an overview of COPD patients that are currently in hospital with a COPD related hospital admission.
- **Scenario 2** provides live reports of COPD related hospital admissions and exacerbations on a population level.
- **Scenario 3** provides an overview of patient-generated data about COPD symptoms, with the option to view an individual patient's data.
- **Scenario 4** provides an overview of an individual patient's previous exacerbations reported by the Hospital, Community Care, and the patient's GP.
- **Scenario 5** provides a history of an individual patient's spirometry test results, undertaken by the Hospital, Community Care, and the patient's GP.

4.4.5 Stage 4 Questionnaire Findings: Evaluation

The following sections outline findings from the two questionnaires from Stage 4 (Evaluation). These questionnaires were given to the 11 HCPs that took part in the qualitative evaluation of the prototype. This included the Realism and Relevance questionnaire (that aimed to understand how realistic each scenario appeared, and how relevant it was to the HCP's role) and the TAM questionnaire (used to supplement the qualitative insights by providing an understanding of what acceptance may be according to theory). The Likert data was interpreted as interval data.

4.4.5.1 Realism and Relevance Questionnaire Results

After calculating the realism scores, results showed on average[19] that all HCPs rated the scenarios as appearing realistic. Likewise, on average[20] each HCP rated the scenarios as being relevant to their job. Overall, the least realistic scenario was Scenario 3 (Patient-Generated Data Overview) and the most realistic scenario was Scenario 1 (Respiratory Ward Overview). The scenario most relevant to participants' job role was Scenario 4 (Example Patient's Exacerbation History) and the scenario least relevant was Scenario 2 (Admissions and Exacerbation Reports). A full breakdown of results from the Realism and Relevance questionnaire is provided below in Table **??**.

On average across all scenarios, C10 provided the lowest rating for relevance, and participant C6 provided the lowest rating for realism. C10 noted that in their role as an Assistant Practitioner, they would not be expected to engage with the five scenarios, hence their low relevance rating across all scenarios. Whereas C6 gave their lowest ratings for Scenario 2 (Admissions and Exacerbation Reports) and

[19] After calculating the mean of each participant's realism scores across all five scenarios.

[20] After calculating the mean of each HCP's relevance scores across all five scenarios.

Scenario		Participant											Average
		H1	H2	H3	H4	H5	C6	C7	C8	C9	C10	C11	
1. Respiratory Ward Overview	Realism	3	3	3	3	2	2	3	2	3	3	2	2.64
	Relevance	3	3	-2	3	2	2	3	3	3	-3	3	1.82
2. Admissions and Exacerbation Reports	Realism	2	2	3	3	3	-1	2	1	2	3	1	1.91
	Relevance	3	1	2	3	3	-1	1	2	3	-3	2	1.45
3. Patient-Generated Data	Realism	1	2	2	3	3	-1	0	3	3	3	1	1.82
	Relevance	1	2	2	3	3	-1	2	3	3	-1	2	1.73
4. Example Patient's Exacerbation History	Realism	3	3	3	3	3	1	0	3	3	1	2	2.27
	Relevance	3	3	3	3	3	1	2	3	3	-2	2	2.18
5. Example Patient's Spirometry History	Realism	3	3	3	1	2	0	1	1	3	2	2	1.91
	Relevance	3	3	3	2	3	1	2	2	3	-3	3	2
Participant Average	Realism	2.4	2.6	2.8	2.6	2.6	0.2	1.2	2	2.8	2.4	1.6	
	Relevance	2.6	2.4	1.6	2.8	2.8	0.4	2	2.6	3	-2.4	2.4	

A score of 3 indicates 'strongly agree', 0 indicates 'neither agree nor disagree', and -3 indicates 'strongly disagree'.

Table 4.4: Realism and relevance survey results.

Scenario 3 (Patient-Generated Data), rating them as 'slightly unrealistic' and 'slightly irrelevant'. During the evaluation with C6, they discussed how they felt sceptical that accurate data could be collected for visualisation in Scenario 2, as some healthcare services do not include all COPD patients in their national audits, where they felt this data would likely be sourced from. Therefore, they believed the data cannot be truly representative of hospital admissions. When discussing Scenario 3, they described their experience of being involved in a number of patient remote monitoring research studies, which were not sustained due to lack of patient engagement. They believed this would be the case for Scenario 3 also. They also believed that Scenario 3 would be difficult to scale to many patients, which would potentially compromise how useful it was in practice. These reasons had impacted how realistic and relevant C6 believed the scenarios to be during the evaluation.

4.4.5.2 TAM Questionnaire Results

The results from the TAM questionnaire indicated that all participants' perceptions of using dashboards to support their work and patient care were positive. A full breakdown of results from the TAM questionnaire is detailed in Table **??** below. The participant with the least positive perception of dashboards was C10, who still 'moderately agreed' that using dashboards could positively support their work and patient care. All remaining participants 'completely agreed' on both questions aimed at scoping their perceptions of using dashboards to support their work and for patient care.

Likewise, on average, all participants found the prototype easy to use and useful. The participant who gave the lowest rating for both usefulness and ease of use was C10 (who on average still 'slightly agreed' that the prototype was easy to use and useful). C10 cited their reasoning as a perceived lack of technical competency in using technology and difficulty distinguishing the colours on the graphs due to an eye condition (though, I did not look at the scores in front of the participants nor did I ask them to justify their scores). Moreover, C10 is the same participant who had scored among the lowest for average 'relevance' of all scenarios in the Realism and Relevance questionnaire, as they acknowledged that they do not need access to most of the data within the prototype in their day to day work, as they were an Assistant Practitioner. This could explain why C10 gave the lowest score for 'usefulness' of the prototype.

According to TAM literature, the positive ratings for 'ease of use' and 'usability' of the prototype would be indicative of participants' motivation to use the prototype in practice, leading to eventual acceptance of the prototype (Davis et al., 1989). However, this finding was not the focus of issuing a TAM questionnaire to participants, and I do not use it to argue for the prototype's acceptability. As discussed previously in section 4.3.6, TAM was used to supplement the richer qualitative findings from the evaluation through providing an indicator of technology acceptance according to theory.

	Participant Average											
Question Topic	H1	H2	H3	H4	H5	C6	C7	C8	C9	C10	C11	Average
Perceptions of Dashboards	3	3	3	3	3	3	3	3	3	2	3	2.90
Usefulness	3	2.75	3	3	2.75	1.75	3	3	3	1.75	2.5	2.68
Ease of Use	3	3	3	3	3	1.75	2.25	3	3	1.5	2.5	2.63

Participant average refers to their average score across each topic.
A score of 3 indicates 'strongly agree', 0 indicates 'neither agree nor disagree', and -3 indicates 'strongly disagree'.

Table 4.5: Results from the TAM survey.

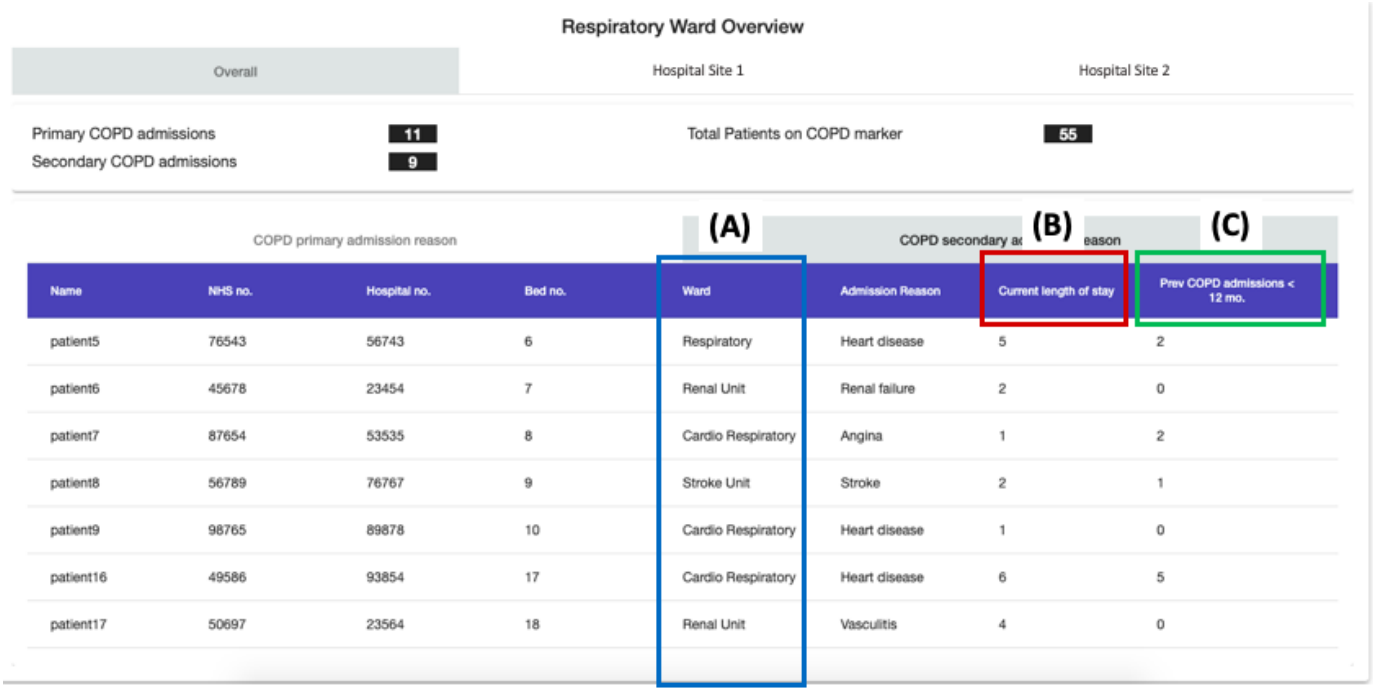
4.4.6 Stage 4 Qualitative Findings: Evaluation

The following sections provide the findings from the discussions during the scenario walkthroughs, which were part of the one-to-one qualitative evaluations with 11 HCPs. Each section is organised in chronological order by scenario number, incorporating the results from the Usefulness questionnaire undertaken in the evaluation. The Usefulness questionnaire was presented to the 11 HCPs at the end of the evaluation, where they were asked to rank the scenarios in order of usefulness to them in their role (a full breakdown of these results are provided in Appendix F).

4.4.6.1 Scenario 1: Respiratory Ward Overview Feedback

Scenario 1 received a joint ranking of first place in the Usefulness questionnaire (alongside Scenario 4: Example Patient's Exacerbation History). Hospital HCPs believed that overall, this scenario would help them to prioritise their day to day workload. For example, the length of stay indicator would help them to understand which patients to target first during ward rounds, with patients with longer lengths of stay being targeted first (Figure 4.11(B)). It would also help them to organise which HCPs should tend to which patients, as H4 described that junior staff and registrar staff could be allocated to help in accordance with each patient's needs (with patients that have a longer length of stay having more complex needs, and more senior staff could tend to them). Similarly, the number of previous COPD related hospital admissions (Figure

4.11(C)) would allow Hospital HCPs to target patients in specific ways. For example, patients with no previous admissions may benefit from education on managing their condition to prevent future admissions. Patients with many previous admissions could suggest that they are reaching palliative stages of their condition, and may not be receiving effective treatment, or have limited support in managing their condition (hence multiple admissions).



(A) lists the ward that the patient is on
(B) details each patients' current length of stay
(C) details the number of COPD hospital admissions each patient has had in the past 12 months

Figure 4.11: Scenario 1: Respiratory Ward Overview annotated.

In addition to this, the easy identification of patients on outlier wards (Figure 4.11(A)) was raised as another way workload could be prioritised, allowing HCPs to become more *"proactive"* (C6) in finding these patients compared to waiting for the outlier wards to call the respiratory ward to inform them that a COPD patient is on their ward.

Community Care HCPs agreed that Scenario 1 could enable them to identify discharged Hospital patients quicker to provide them with follow up care. This contrasted with current practice, where they have to *"trawl"* (C7) through a list of flagged COPD patients on the marker system to understand why patients have been admitted to hospital, to decide if it was necessary to follow up with the patient on hospital discharge (i.e. if the admission was not related to COPD, there would be no need to follow up with specialised COPD care). C7 suggested that the prototype could be improved by providing Community Care with a view which listed discharged COPD patients, so that they had an organised list which they could work from (this compared to the current list which had patients that were still in Hospital and are not ready to receive follow up support from Community Care).

However, a notable challenge highlighted by HCPs was that data generated in clinical settings can often be incomplete and unspecific, which can affect how they engage with it and use it for decision-making. Knowing which data source would be used to facilitate Scenario 1 was important for HCPs so that they could acknowledge the respective drawbacks when making decisions based upon it. When discussing viewing patients listed in Scenario 1, it was highlighted that the existing data sources that could feasibly facilitate the scenario both have noteworthy inaccuracies. For example, there were two methods that could identify if a patient has come into hospital due to COPD that could facilitate Scenario 1. The first is through the Hospital COPD marker system, which keeps a list of patients flagged as having COPD. The list was first populated by data from local GP practices, where patients who were diagnosed with COPD at their GP practice were then added to the marker system. The list is then shared with the Hospital and Community Care, who can add patients (as a result of a COPD diagnosis) or remove patients (if they are shown not to have COPD). However, it was noted that there are three main reasons why this was not a *"true list"* (C7). The first was that patients on the list sometimes *"have other respiratory conditions"* (C11) instead of COPD. The second related to how there are *"patients within the Hospital that haven't had the flag added [to their name]"* (C7) as the marker system is not *"utilised very well"* (C7) in how it is operationalised, as it is a manual

process, and *"there will be patients that probably slip through the net"* (C7). The third related to uncertainty around the validity of the original diagnosis of COPD at GP practice level. These factors each made the marker system seem appear an unreliable data source for Scenario 1.

The second data source that could facilitate Scenario 1 was data from the clinical coding department at the Hospital, but this was thought to be unspecific and often initially inaccurate. For example, the initial coding of the patient's admission reason is based on what senior decision-makers in the emergency department write, who are *"generalists"* (C6) and can only devise a working diagnosis for the patient that is not intended as the finalised admission reason. Clinical coding involves assigning a code describing diagnoses according to a classification system such as ICD-10 (World Health Organisation, 2019). It was also acknowledged that there are *"very umbrella type codes"* (C6) within current classifications systems, that mean that there are multiple codes that are used to describe a single hospital admission, which has *"has been an issue, always"* (C6) and is not a problem that is specific to COPD. To illustrate, COPD can be clinically coded both as 'COPD' and 'breathlessness' separately, which means that there may be COPD patients who do not receive a 'COPD' code. In this case, they may be missed from the dataset used to populate Scenario 1. However, it was highlighted that the data produced from the coding department generally becomes more accurate as a patient's admission progresses, as HCPs *"get more information during the course of somebody's admission"* (C6) and can amend the code to reflect a more accurate reason for admission.

4.4.6.2 Scenario 2: Admissions and Exacerbation Reports Feedback

Scenario 2 was ranked as the least useful scenario in the Usefulness questionnaire. When explaining the decision for a low ranking, participants mentioned that the scenario had less impact in their day to day work and was less meaningful for individual patient care (though the scenario was still useful to them). They discussed that they would not access this scenario on a daily basis in their role, and it would be checked

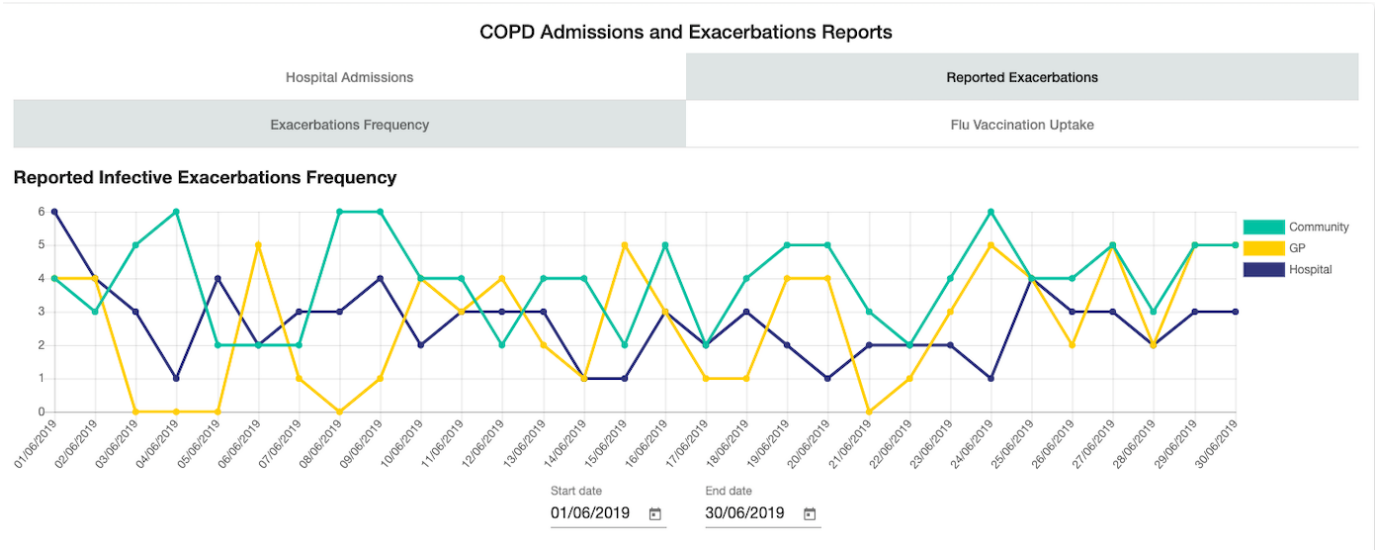
on more of a *"monthly"* (H4) or *"six-monthly basis"* (H2). The main perceived benefit for this scenario was the ability to support strategic planning, such as *"what [resources] do we need, how do we improve services, where do we plan our service, how do we improve our pathway to get more staff in and more services"* (H4) and forecasting admissions as *"GP spikes normally occur slightly before admission spikes so if there is starting to be a GP spike then you can follow the trend"* (H5). For Community Care HCPs, this scenario had most potential to see *"where people are referring themselves into, where they are ending up, that first presentation, and does work need to be done to meet particular needs, so do we need to be promoting this service more"* (C9) and *"looking at winter trends and things like that"* (C7) so that if there are spikes Community Care could *"issue business continuity plans and things like that"* (C7).

Though all participants agreed the scenario was useful, C8 highlighted that they believed that themselves and colleagues would require training to understand the data that was being presented in order to incorporate it into strategic decision-making (Figure 4.12). They noted that they were *"not used to seeing data like this"* (C8), expressing that the volume of the data across all three services (Hospital, Community Care, and GP services) looked *"a bit frightening"* (C8).

A major challenged raised regarding this scenario was the belief that the Hospital, Community Care, and GP practices do not have a shared, consistent understanding of what constituted a COPD exacerbation. HCPs strongly believed that this affected the quality of exacerbation reporting, as some patients were labelled as having an exacerbation *"too easily"* (C9). For example, H4 and C11 discussed their concerns over the way that exacerbations are currently labelled and how this impacts how they would engage with this data in practice:

> *"It's easy to label them as [having] an exacerbation and give them a little bit of steroids and a little bit of antibiotics ... that's why it comes back to how much do you trust the person who is saying they have taken it seriously and taken it to say this is an actual [COPD] exacerbation?"* (H4)

> *"I also do feel like from a professional side that medics are like well we'll*



The current view is set to a graph indicating the reported exacerbation frequency over time reported by the Hospital, Community Care, and GP practices.

Figure 4.12: Scenario 2: Exacerbation Reports tab.

give you this because it'll move you on through and out the system." (C11)

One explanation offered for the discrepancies in labelling exacerbations was that not all HCPs involved in patients' care will be specialised in COPD. As such, the Hospital and Community Care HCPs' specialism in COPD is what made their identification of exacerbations most reliable, compared to GP practices and emergency department staff who *"aren't specialised in every condition"* (H1). C11 discussed the ways in which a patient's symptoms may be classified as an exacerbation by some HCPs but not others, which can lead to differences in how they are reported:

> *"People tend to be treated unnecessarily we do find. Patients that we are monitoring at home, that we don't feel are clinically exacerbating, but they want something treatment wise, and then they will present at the GP or Emergency Department and get that treatment so I do think there's a bit of discrepancy [of what exacerbations are] there."* (C11)

Whereas H1 described that some HCPs who have less *"expertise"* with COPD

may assume the patient *"knows their condition best"*. As a result of this, H1 explained that some HCPs will prescribe exacerbation medication to the patient when the medication may not have been necessary. This would in turn be incorporated as exacerbation data within the scenario, which may not be an accurate reflection of what the patient experienced.

For the HCPs, not knowing if an exacerbation has been accurately identified meant that they were not confident in relying on this data for decision-making. They felt that inaccurate exacerbation reports could project an overestimation of the number of exacerbations occurring in their region, which could lead to *"overspending"* (C7) on resources to adjust. However, they did agree that the visualisations provided by Scenario 2 could be used to help HCPs across the different healthcare services to educate one another as to why a consistent terminology is needed, and the impact that inaccurate data can have on the services and patients.

Another notable challenge with Scenario 2 was that it collated data from different collaborating organisations (the Hospital, Community Care, and GP practices), which led to concerns over potential duplication of certain data that could render misleading visualisations. While discussing the graph that depicts population level exacerbation reports in Scenario 2 (Figure 4.12), C6 noted that *"you could have the same patient in three datasets there"*, as patients could visit their GP and be treated for an exacerbation, deteriorate, and end up being treated by Community Care, and then be referred to Hospital. This would create three separate data points for the patient for one single exacerbation, which would then be visualised thrice on the scenario.

4.4.6.3 Scenario 3: Patient-Generated Data

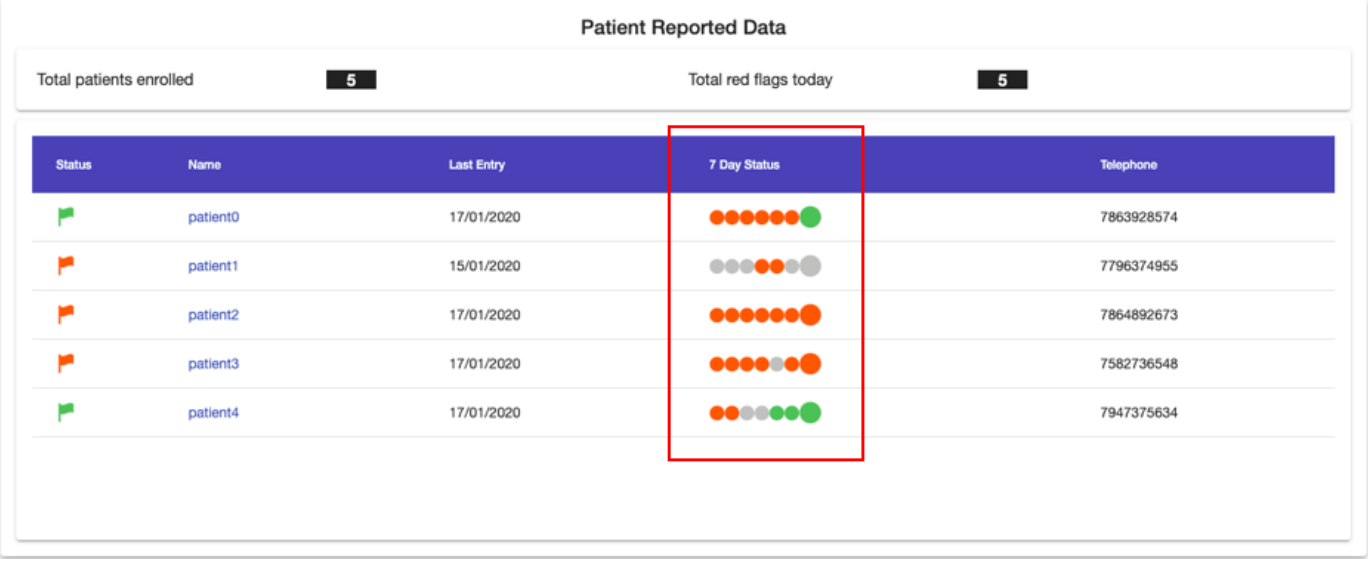
Scenario 3 was ranked second most useful in the Usefulness questionnaire. Most participants believed that this scenario would be very valuable in providing an understanding of the whole patient experience of living with COPD, followed by the early identification of patients that are struggling to manage their condition. They particularly liked the way that the traffic light system could provide a quick review of patients'

symptoms, allowing them to quickly identify and focus on patients who seem to be experiencing difficulties (Figure 4.13).

There was discussion among participants about how this scenario could help to avoid hospital admissions through the early identification of flare ups, and even be used as an educational tool to help patients self-manage their condition better. For example, the log of individual patient entries can facilitate discussions between the HCPs and the patient as to what actions to take when the patient is experiencing a specific symptom. While looking at the dummy data of a patient's entry (Figure 4.14), H4 saw an example of a hypothetical patient that contacted their healthcare team without experiencing any symptoms. They discussed how they believed the patient may be experiencing anxiety and as a result required *"assurance"* from a HCP, and that they could use this data to probe discussions in clinic with the patient. Similarly, C6 described value in using the patient-generated data in the same way as H4:

> *"You could use it [patient-generated data] to talk to them and educate them, and say, well you're reporting that you are terrible, why is that? And if they say well I'm reporting that I'm feeling terrible because I've had an argument with my husband, then you can say well that's interesting and I'm sure that does make you feel unwell, but here's some breathing techniques to help when you're anxious, but it's not an exacerbation... So yeah you could use it as an entry to a conversation."*

HCPs discussed that it would be important to identify the correct patient group to be enrolled onto self-monitoring set ups as in Scenario 3, as HCPs agreed that the scenario could not scale to all patients on their service as it would lead to *"unmanageable numbers"* (C9). The types of patient groups that were believe would benefit most from self-monitoring were mainly severely ill patients that have had several hospital admissions. It was also raised that patients could be enrolled on the system for a specific period of time as encouragement, rather than participating for an indefinite amount of time. For example, C9 suggested that Scenario 3 could be *"practical"* if patients *"could be put on it for a month and monitored by the Community Care team"* to combat 30 day hospital re-admissions rates that occur with COPD (Rezaee et al.,



Highlighted is the traffic light system which depicts each patient's seven day status. Red indicates symptomatic, green indicates asymptomatic, and grey indicates no data has been entered by the patient.

Figure 4.13: Scenario 3: Patient-Generated Data Overview.

Highlighted is an example patient's day type on 20/04/2019, followed by the action the patient took on that day as a result of their symptoms.

Figure 4.14: Scenario 3: Individual Patient Log.

2017). There was also potential identified for newly diagnosed patients to use this system to become familiar with their symptoms. However, all HCPs agreed that they would be most willing to enroll severely unwell patients onto a system like Scenario 3, compared to the average patient who can manage their condition on their own. There was a notable concern raised by H5 and C6 that recording this type of data may be *"medicalising their condition"* (C6). This may not be *"constructive"* (C6) for some patients, as *"some don't want to be reminded that they are ill"* (H5).

This directly leads to the second challenge about expectations around monitoring the patient-generated data in Scenario 3. Though HCPs identified that one of the benefits of Scenario 3 would be the early identification of patients that were unwell, HCPs had concerns about how they could realistically allocate time to review each patient on the system each day. C6 highlighted that set ups like Scenario 3 are *"implying somebody is monitoring it"* and patients *"may become dependent upon"* the idea that a HCP is monitoring their health and *"looking at that [data] and acting"*. C6 expanded on this:

> *"Self-management sounds great, in reality it means a clinician managing them. That isn't self-management, is it? *pointing to the screen at Scenario 3*. A clinician is looking, or supposed to be looking at that and acting. Mmm. I mean you can make an argument well the patient is looking at it too, and it would hopefully prompt them to take action, yeah fair enough I get that, but fundamentally they aren't fully self-managing under this sort of scenario."*

Both C6 and H2 suggested that the scenario could incorporate filters that alert them when patients have *"gone from green to red"* (C6) or based on *"an agreed parameter where there was three days of red or five days of red"* (H2), as this would provide a proactive way of *"highlighting an issue"* to HCPs, rather than relying them to check themselves. However, C6 noted that this could still lead to *"unmanageable numbers"* and hence ensuring that the right target population used the app at the right time was crucial. Similarly, the potential time required to investigate a patient who was not compliant with data entry was another concern. C7 felt concerned that a

patient that was no longer inputting data could *"potentially be home isolated, and be dead potentially"*. Following on from this, C6 described the labour intensive process that would be required to reach the patient in these instances:

> *"Say somebody has three grey days [no data input] one after the other, they have to have a phone call, otherwise it's meaningless, you've got to do something with this data. So, fine alright. You ring them up and they don't answer. Really common, patients often particularly in the days of mobile phones, it used to be better when people had landlines, but now with mobile phones, people just block you or don't answer if they don't see your number. So you try, and you try, and you maybe try every day for a month. At some point, you are gonna have to send them a letter or do something else. So you generating a whole heap of work, and then what will tend to happen is you'll get through to the patient who will say 'ah yeah I didn't bother I'm not bothered about it anymore.' ... as a service manager, you've got to decide where's the most appropriate use of your resources, so the issue with telemonitoring or telehealth is that it can be very monitoring heavy for very little beneficial outcomes."*

On a related note, HCPs discussed the differences in using sporadic data versus consistent data entered by the patient for decision-making. While patient compliance in engaging with data reporting was described as the *"denominator of success"* (H5), some HCPs believed consistent data entry was key for a *"true overall reflection"* (C10) of how the patient is doing, while others felt sporadic entries were acceptable so long as the patient inputs data when they are symptomatic. The boundary of acceptability differed depending on what the patient-generated data would be used for. For example, for the purpose of remotely monitoring a patient and intervening where necessary, sporadic data was seen as acceptable so long as the symptomatic days were *consistently* reported by the patient:

> *"If you have loads of grey [no input] and then three red, you know you need to phone them ... but there will also be patients who just don't put data in until they are unwell. What you don't want is patients who put greens*

[days] but don't put the red." (H5)

Community Care HCPs also reported that for the purpose of monitoring a patient from the clinic, asymptomatic days (green days) could be *"hidden"* (C9) from the Scenario 3 (Patient-Reported Data) view, as *"there's no need to worry about them"* (C9) and the priority was to see the patients reporting symptomatic days (red days) as those are the *"patients that needs to be viewed"* (C7) and contacted. This further supported the notion that consistent reporting of symptomatic days was important for decision-making in this context, without necessarily requiring consistent reporting overall. For the purpose of reviewing a patient in a clinic setting, consistent reporting overall was seen as more important compared to sporadic data entry. It was acknowledged that COPD is a *"variable"* (C8) condition and without daily input, HCPs *"couldn't be so sure about the day to day changes"* to the patient's condition. These day to day changes were important for the HCPs to build a picture of how patients are managing their condition to better understand their quality of life. They also noted that encouraging the patient to record green days can allow them to collaboratively review the data with the patient and emphasise the positive periods of their life.

There were also trust concerns around using the patient-generated data for decision-making, particularly the difference between self-assessed data (based on patient judgement) and physiological data (backed by quantitative measurements). Although self-assessed data was initially outlined as a need from the HCPs in Stage 2 (Priorities and Implementation Challenges, section 4.4.2.4, pg. 101), HCPs perceived self-assessed data as less reliable for clinical decision-making due to the fact that patients' perceptions of their condition can affect the data that they record. For example, HCPs discussed the variability and subjectivity that arises with self-assessed data around factors such as rating breathlessness and fatigue. H6 voiced concerns that data within Scenario 3 would require some form of standardisation to account for this variability as *"some patients will over-report their symptoms, and some will under-report their symptoms."* Whereas C8 discussed the challenges in identifying individual patient symptom thresholds and the organisational guidelines which would effect how the data is used for decision-making purposes:

> *"What is drastic to somebody is nothing to somebody else. It's so variable. Whereas you know physiological data, you've got a guidance that you can say 'that's acceptable, that's not acceptable"'*

It was further raised that self-assessed patient-generated data *"doesn't filter out things like depression"* (C6) and the *"huge psychological element"* (H2) which *"some people struggle with"* (C6) and thus can impact how patients assess their symptoms. HCPs noted that readings which are affected by factors outside of the patients' COPD *"doesn't mean they don't have a genuine need"*. Rather, it becomes a challenge for what respiratory HCPs *"can draw out from the data"* in regards to the patient's COPD. In a remote monitoring context, it would make it challenging to understand which patients require attention from a respiratory perspective or a social care perspective. Although HCPs felt they could not rely on self-assessed data alone for decision-making, they did note that there was significant value in viewing self-assessed data. They discussed the importance of understanding the patient's own perception of their condition, noting that without self-assessed data the *"emotional value"* (H4) and what the patient is *"experiencing"* (H4) is lost, an aspect that still must be understood as part of chronic care management. However, the psychological factors resulting from COPD required different management support compared to clinical exacerbations, thus knowing which data could be influenced by psychological aspects of the condition is important for decision-making.

One way in which HCPs felt patient-generated data could be more reliable for decision-making was through pairing self-assessed data with physiological readings from the patient. Physiological readings, such as pulse oximeter readings (which measure oxygen saturation) were seen as being able to provide a *"baseline"* (C11) to compare a patient's perceived breathlessness against, which can help to differentiate the type of support the patient needs. H2 elaborated on this concept:

> *"If someone was telling me they feel absolutely awful and are scoring reds (pointing to screen), but actually their physiological parameters were fine, I'd feel more reassured that perhaps they aren't clinically deteriorating, but obviously I still need to address the fact that the patient feels like they are."*

Some HCPs believed that the pairing of self-assessed and physiological readings could create a more *"meaningful"* (H4) dataset from the patient, as both aspects of this data cover the experience of living with COPD and *"you want to merge both what they feel or experience to what is actually happening"* (H4). Likewise, H2 agreed that pairing both types of data together would provide a *"more of a well-rounded picture"* of the patient's condition that could help to decide how to proceed with their care and which type of support the patient should receive (e.g. exacerbation management support, psychological support, or social support).

4.4.6.4 Scenario 4: Example Patient's Exacerbation History Feedback

Scenario 4 was also the highest ranked scenario in the Usefulness questionnaire. The positive feedback centred mostly around being able to better understand the patient's journey *"and how patients' quality of life and clinical health has been affected across all sectors of care"* (H5) as HCPs tend to see the patient at specific intervals and *"what you don't see is what's been happening, and how many times"* (H5). This was particularly valuable given that COPD is a chronic condition that is managed by a diverse team of HCPs at different stages, and having *"the overall picture rather than just snippets of information"* (C8) was seen as important for effective care planning and patient management. Scenario 4 was thought to provide an easier way to identify the patient's previous exacerbations, which was a direct improvement over the current method of asking the patient for their history and shuffling through *"thousands of records"* (C6) about the patient which contains detail that is too *"heavy"* (H5) and *"stuff [that] is not relevant for what we [respiratory HCPs] are interested in"* (C6).

A further benefit of Scenario 4 was the ability to identify which patients are severely struggling with their condition and may require a referral to secondary care (C9) or *"are heading towards more palliative end stage disease"* (H4) and need *"advance care planning"* (H3). The collation of exacerbations in this way was thought to be *"very, very useful"* (H4) in supporting decisions around the next steps for the patient's care, but also for better understanding the patient's story of living with the condition. H4

envisioned using Scenario 4 when engaging with patients within clinics, whereby *"you sit with them to say tell me what happened there"* to learn their story. This was seen as a valuable tool, as patients often *"forget"* (C7) and their *"recall isn't always great"* (H3), which impacts how well they can articulate their experiences. H4 described using the data in a way that promotes the collaborative detangling of the patient story to identify specific actions (or inactions) that impacted their COPD:

> *"[The patient may say] I went away on holiday, and was in the bus or the coach, and this other person was coughing next to me... so you can understand ok what happened there? Did you forget to take your inhalers is that how you ended up having a non-infective exacerbation, what happened there? ... [or] ... if they are only breathless because they have seen something on the television that upset them, that may not physiologically be there, but that has been there on their mind and that has affected the way that they are feeling, but physiologically they don't need steroids."*

A notable concern with Scenario 4 related to misinterpreting the number of exacerbations a patient has had within a time period. As the data within this scenario was collated from the Hospital, Community Care, and GP practices, there were similar concerns as with Scenario 2 (Admissions and Exacerbation Reports), whereby one exacerbation could be mistaken for multiple exacerbations. HCPs described that the list in Scenario 4 presented each entry as an isolated exacerbation, yet multiple could be *"the same exacerbation"* (C6). For example, a patient may visit their GP about an exacerbation, receive medication, and end up in hospital for that same exacerbation, leading to two separate data entries in the scenario. However, this concern was thought to have less severe consequences than those associated with Scenario 2, as HCPs felt they could use their judgement to sieve through the entries and *"say well two of them or three of them were really close together so we'd actually say that's probably part of the same exacerbation that we just weren't treating effectively"* (C9).

4.4.6.5 Scenario 5: Example Patient's Spirometry Results Feedback

Spirometry results were seen as the third most useful scenario according to the Usefulness questionnaire results. Discussions with HCPs revealed that the reason for a lower rating was due to the lack of impact the scenario could have to the patient, as *"it's not a functional tool"* (H5). Though HCPs still described the scenario as being *"really useful"* (H5) and time saving, just comparatively less impactful than Scenario 1 (Respiratory Ward Overview), Scenario 4 (Example Patient's Exacerbation History), and Scenario 3 (Patient-Generated Data). All participants agreed that the trace of the result alongside the numerical results was valuable in determining the *"quality"* (C9) of the test, as *"having the tracing to see is really important because you obviously don't know how the patient performed [during the test]*[21] (C11). It was also noted that providing all results in a table format allowed for an easy compare and contrast of how the patient's lung function may have deteriorated over time.

An important challenge raised around Scenario 5 was that HCPs generally felt that spirometry data was more trustworthy if it was recorded within their own department. However, HCPs also preferred spirometry test results that was recorded by HCPs which they had a close working relationship with (which could be HCPs in different departments and organisations). For example, C7 and H2 discussed how they believed having a stronger working relationship with a particular HCP or service would mean that the data was more *"familiar"* (C7) and as such, they would be more confident in using it for their decision-making. C7 discussed that their close working relationship with the Hospital HCPs made the spirometry tests performed by them seem more reliable (compared to tests taken by GP practices), as they were familiar with the Hospital HCPs' specialisms and competencies. When discussing using the data within Scenario 5 for decision-making, C7 described how they placed confidence in test

[21] Spirometry tests require three forced blows into the spirometer device, and how the patient blows can affect the reading.

results from the Hospital over GP practices:

> *"I can see on this one (pointing to spirometry results on the screen) that this was done here [in Community Care], and this one at the Hospital, so you'd be more inclined to use the Hospital data as kind of reliable, that's your reliable one, then you can probably work from that as to whether or not the others were really done properly."* (C7)

In the example above, C7 used the Hospital spirometry test result as a baseline to compare and contrast the rest of the data with, in order to decide whether the rest of the data was reliable. This demonstrates how the HCPs place different weights or *"confidence intervals"* (H4) on the data depending on its source (despite the *type* data being the same). This same thought process was seen with C9, C8 and H5 when comparing spirometry test results:

> *"Was that [spirometry test] actually done by the Hospital or Community Care? In which case, then it's reliable. Otherwise, it might have been a GP."* (C9)

> *"I definitely believe what came from the Hospital over the GPs."* (C8)

> *"I think it [reliability] is a big issue and it depends on, I know you've got who's done the trace, so I think that gives you an idea of the reliability of it."* (H5)

4.5 Discussion

The following sections collate the findings across all stages of the study into three main discussion points: (1) 'trusting data for clinical decision-making', (2) 'integrating systems into workflow', and (3) 'reflections on evaluation approach'. These discussion points, grounded in the findings from this study, aim to highlight salient challenges and opportunities for DSDM technologies to support respiratory care.

4.5.1 Trusting Data for Clinical Decision-Making

A prevailing theme throughout this study has been the concept of 'trusting' data and how this influences whether HCPs will use certain data for decision-making. That is, trusting its *author* (who recorded the data), and its *source* (what system the data originated from), which helps to determine data reliability. Trust can be defined as 'a subjective assessment of the reliability that a person or system will perform an expected action' (Knowles, 2016).

Trust and technology has been explored extensively in past research, particularly in relation to its impact on users' engagement with digital health technologies or health information. For example, trust in health information shared and published on the internet (Crawford et al., 2014; Sillence et al., 2013; Smith and Manna, 2004), trusting the accuracy of patient-generated data (West et al., 2016), trusting the validity of data originating from sensors in personal health technologies (Clifford and Bishop, 2011; Jaigirdar et al., 2019; Knowles, 2016), distrust in the advice of non-specialist HCPs by patients (McNaney et al., 2018), and trusting computer assistance in medical decision-making (Hartswood et al., 2003b; Yang et al., 2016).

However, my research has discovered how HCPs may distrust data held in their clinical systems, and data produced by their colleagues and patients. The sections below describe where trusting data was a key concern to HCPs, followed the implications for the design and deployment of DSDM technologies for respiratory care.

4.5.1.1 Healthcare Professionals as 'Data Authors'

The trustworthiness of data generated by HCPs depended upon how competent they were perceived to be in relation to understanding and assessing COPD. When HCPs were 'data authors' (responsible for recording data), their competency levels were determined by their professional role, and how reliable the data recorded from members of that role have been in the past. Data recorded by the ward staff at the Hospital (perceived as highly specialised in COPD) was considered the most trustworthy,

while data generated by GPs (perceived as less specialised in COPD) considered the least trustworthy. This concept of trusting data based on professional roles strongly resonates with findings by Cicourel (1990) and Ellingsen (2003a,b), which discussed how the source of medical information determines its adequacy for use in decision-making. More specifically, Cicourel (1990) observed how the perceived credibility of information was based on social and professional hierarchies within a teaching hospital. For example, diagnostic information from attending physicians was rarely challenged and perceived to be more 'objective' (pg. 228) than that of medical students. Whereas Ellingsen (2003a) expanded on Cicourel (1990)'s findings, demonstrating how physicians were reluctant to use information recorded by their trainees due to perceived inexperience. Both studies show how information recorded by senior and experienced HCPs can be perceived as more 'trustworthy' in hospital contexts.

Adding to these findings by Cicourel (1990) and Ellingsen (2003a), I have discovered that HCPs' *medical areas of specialism* can influence the perceived trustworthiness of data. For example, spirometry tests undertaken by COPD nurses (an expert in their domain and highly specialised in COPD care) were deemed more trustworthy than those undertaken by a GP (an expert in their domain but not specialised in COPD). As the GP's clinical specialism is not COPD, rather they are experts in general medicine, they were perceived as less likely to produce trustworthy data about their COPD patients. GPs may be less likely to be trained in conducting spirometry tests as this forms a very small part of their role, compared to COPD nurses who may conduct these daily. Similarly, their lack of specialism in COPD was perceived to make them less likely to be able to accurately identify a COPD exacerbation. In short, the GP is thought to be less knowledgeable in COPD care, and although a medical expert, information that they produced about COPD was considered less trustworthy. This was also observed in how HCPs perceived the information received by emergency department staff at the Hospital.

Further to this, some HCPs believed that they could better assess data trustworthiness if it was produced by a colleague whom which they had a close working relationship. When staff have a close working relationship with one another, they are

able to assess each other's specific skills and competencies. Though this ultimately relates back to how trust depends on perceived competencies, it demonstrates an additional social dimension to this phenomenon. This social dimension inadvertently produces bias against information produced by the GP, as Community Care and the Hospital do not collaborate closely with them. This relates to the concept of 'biographical familiarity', which is described by Jirotka et al. (2005) as a 'predicate' for trust. In their work, Jirotka et al. (2005) observed how mammogram readers developed a sense of familiarity of the strengths and weaknesses of their colleagues, which affected how they judged and oriented themselves to reading mammograms produced by those colleagues. They found that contextual information about the production of the mammogram (such as the reading centre that produced the scan) had relevance for how the mammogram would be interpreted during reading. In my research, a lack of biographical familiarity had direct implications for how willing HCPs were to engage with data produced by staff whose competencies they were less familiar with. The Hospital and Community Care could better trust each other's clinical judgements as they had a close working relationship and shared the common goal of quality care and admission avoidance for COPD patients. This contrasts with how they perceived data recorded by the GP or emergency department staff, whom which they collaborated with less and had different specialisms to.

As I have highlighted, HCPs trust data differently depending on the data author. This has direct implications for the design of DSDM technologies for healthcare, and we must be mindful of how to represent such data in DSDM technologies as the same data may not be weighted equally. In the prototype, I included the 'source' of spirometry test results and exacerbation reports, which HCPs felt was crucial metadata to emphasise next to the collation of this information. However, including the source *accommodates* these trust concerns, rather than provides a mechanism for alleviating or eliminating them. It is important to note, however, that this trust observation is social in nature. Therefore, though this observation has direct relevance for how we design DSDM technologies, it cannot be 'fixed' through a technical solution alone. In a future where better education and training around COPD can occur, one way to technically

support collaborating HCPs begin to better trust each other's data could be through the use of digital badges, similar to those seen in online communities (Anderson et al., 2013). These badges could identify, for example, which healthcare organisations have undergone certified technical training in spirometry tests. These could be displayed next to data entries recorded by the healthcare organisation. This could support trust building, by slowly eliminating the 'blanket approach' currently undertaken, which is to question data generated by a particular source.

It is important to acknowledge that this concern around trusting data authors is a very nuanced problem, which is unlikely to be solved by a number of proposed design solutions in this thesis. I argue that what we can learn about the existence of these trust issues, and what this means for DSDM technologies, is the important point to emphasise here. Though the HCPs in this study strongly believed that collation of data collected by all HCPs in the patient's care network would support decision-making, in reality there were concerns over the reliability of certain data. I raise the need for the HCI community to become better aware of how trust impacts the use of cross-organisational and cross-departmental data in healthcare. This is particularly relevant for care of chronic conditions, whereby there may be many collaborating HCPs that have different areas of medical specialisms. This will ultimately impact human-data interaction for DSDM technologies for healthcare, and perhaps digital healthcare technologies more widely.

4.5.1.2 Patients as Subjective 'Data Authors'

Patient-generated data was thought to offer a rich perspective about the overall patient story, which helps to understand the severity of their condition and support individualising their care. However, the Stage 4 evaluations uncovered trust concerns around patients generating their own data to share with HCPs for decision-making. This concern was specific to the self-assessed data items included in the prototype: 'increased breathlessness', 'increased cough', 'increased sputum', and 'sputum colour'. This trust concern ultimately stemmed from HCPs believing that patients' self-assessed

judgements of their symptoms were too 'subjective' and contained too much variability to use for decision-making. It was a challenge for HCPs to identify whether a patient was likely to under-report or over-report their symptoms, which would directly impact how their symptoms were represented in the data. In fact, Nadarajah et al. (2019)'s study on telemonitoring of COPD patients showed how some patients themselves had difficulty in responding to 'subjective' questions about rating their breathlessness and coughing, and would choose to under-report their symptoms unless there were large deviations from their usual baseline symptoms. Likewise, it is conceivable that there are patients that would over-report their symptoms in response to dealing with uncertainty around subjective measurements. This shows that subjectivity in patient-generated data is a challenge for both COPD patients and HCPs.

One way that HCPs thought variability in patient-generated data could be mitigated is by pairing this data with quantitative readings. For example, using pulse oximeter readings to numerically represent the breathlessness symptom. Pairing self-assessed data with physiological data to predict respiratory exacerbations has been used in previous work with promising early results (Anastasiou et al., 2018; Velardo et al., 2017). For example, by pairing symptom diary data with either pulse oximeter readings or peak flow readings. Going forward, it is important to work with HCPs to understand the symptoms that are valuable to track, and map how these may be recorded to a degree of accuracy that the HCP can use for certain types of decision-making. The dataset which was used to represent patient-generated data in Scenario 3 was based on data from an existing symptom monitoring app for COPD[22], and some criticisms raised by HCPs in this study will be specific to the type of data explored in the evaluation. However, the symptoms explored in this study, particularly breathlessness, are all measured in COPD clinical assessment questionnaires (Bestall et al., 1999; Crisafulli and Clini, 2010; Jones et al., 2009; Kendrick et al., 2000) and are

[22] 'How Are You Today?' Accessed Februrary 6, 2020 from https://play.google.com/store/apps/details?id=com.intelesant.copd&hl=en_GB.

used in formal definitions of what constitutes a COPD exacerbation (Pauwels et al., 2004). Therefore, discussions about the specific symptoms explored in this study in Scenario 3 can be used to inform future work around using these indicators for decision-making.

An area where subjective and variable patient-generated data would be problematic is for predicting exacerbations, something which HCPs expressed interest in using this data for. Previous work has shown how clinical data may be used to predict COPD exacerbations (Amalakuhan et al., 2012; Garcia-Aymerich et al., 2001; Kerkhof et al., 2015), with the strongest predictor of exacerbation risk thought to be the frequency of exacerbations the patient has had in previous years (Amalakuhan et al., 2012; Kerkhof et al., 2015). These predictive systems require patient data that is recorded in a consistent and standardised format, such as patient data held within primary care records (Kerkhof et al., 2015). However, when patients are in charge of generating their own data for this purpose, any subjectivity and variability in reporting could hinder the accuracy of the predictions made by the systems[23]. As such, there would be a requirement to collect data that is perceived to be more 'objective' as part of this process, such as quantitative readings. It is important to note, however, that quantitative readings can also be subject to inaccuracies or variability, for reasons such as improper calibration of equipment and differences in device algorithms (Marcengo et al., 2016; West et al., 2016). Information about the context in which data was recorded is also important to understand situational factors that may impact readings (West et al., 2016). For example, as raised by one HCP, anxiety can influence symptoms such as breathlessness (C6, section 4.4.6.3, pg. 120). Therefore, when using patient-generated data for the purposes of predicting exacerbations, the data should have minimal variability and account for the context in which it was collected. Minimising potential inaccuracies can be achieved through the collection

[23]It is worth noting that data collected by HCPs, particularly about COPD exacerbations, can also be variable (see section 4.5.1.1).

of multiple physiological readings which can provide a less ambiguous picture of the patient's health. However, this increases burden on the patient to record additional data (Lupton, 2013). Depending on the COPD patient population who engage with this technology (e.g. severe patients at high-risk of exacerbation versus mild patients at low-risk), different levels of engagement with self-monitoring may be considered more acceptable and worthwhile. Yet, this does not lessen the need to consider the patients' perspective when designing technologies to predict COPD exacerbations.

Subjectivity in patient-generated data may be somewhat acceptable in particular clinical scenarios. Accessing this data in clinic with a patient, as *"an entry to a conversation"* (C6, section 4.4.6.3, pg. 120), was thought to help explore how a patient is managing their condition in their everyday life. This insight could help HCPs identify opportunities where the patient may require extra support, such as improving education around self-management. Here, the data alone is not used to drive the decision-making process. Rather, the data becomes a tool that can support patients to structure storytelling about their symptoms and experiences. The design of Scenario 3 enabled this, as patient-generated data was provided in a standardised format[24], which highlighted to the HCPs any variations in a patient's symptoms graphically. This allowed HCPs to quickly identify areas to query the patient about.

This aligns with work by Mentis et al. (2017) about using activity trackers to understand movement of patients with Parkinson's disease. Their work showed that patient-generated data can be an useful resource for HCPs and patients to co-interpret to identify personalised management strategies and health goals. However, they discussed the need to support patients to better understand their data prior to clinic visits to maximise the value gained from the co-interpretation process. This is important in the context of COPD, as HCPs had noted that patients' recall of their

[24]In reality, patient-generated data can only be in a standardised format if COPD patients use the same monitoring technology. This is not completely out of the question, as healthcare organisations may look to endorse specific technologies for monitoring chronic conditions (see Chapter 6).

symptoms tends to be poor (C7 and H3, section 4.4.6.4, pg. 127). To support COPD patients to understand their data in preparation for clinic visits, self-monitoring technologies could prompt patients to optionally input free-text to accompany their symptom data. Through providing contextual information in addition to monitoring symptoms, patients can be reminded of any notable events or experiences to discuss in clinic. However, it is important to recognise the liability concerns that HCPs may face when viewing free-text notes sent by the patient, as they may perceive themselves as liable for the content (Marcu et al., 2011). To mitigate this, the patient-generated data shown to the HCP could be refined to exclude free-text narrative. Alternatively, a system could operate where these free-text notes would only be made available with the patient present in a clinic.

4.5.1.3 Patients as Sporadic 'Data Authors'

A notable practical challenge with patient-generated data is the effort perceived to be necessary to keep patients generating data consistently, so any patterns can be accurately identified (Stone et al., 2002, 2003). Thus, sporadic data entry by patients can create a challenge for using this data in clinical settings as important insights may be missed, or considered ambiguous due to missing data (West et al., 2018). However, when exploring Scenario 3 with HCPs, I found that sporadic data was sometimes considered acceptable. It was raised that being able to identify a patient's 'bad days' was most important, and if the patient *consistently* entered data when they felt unwell, this was usable. This was summarised by one HCP as: *"what you don't want is patients who put greens [days] but don't put red [days]"* (H5, section 4.4.6.3, pg. 123). Further to this, some Community Care HCPs suggested that the Scenario 3 could be improved by offering functionality that allows HCPs to filter asymptomatic patients from the collated list. Although understanding that a patient feels well is of interest to the HCPs, there was a stronger interest to know when a patient felt unwell, as this requires some action or intervention from the HCP. Adding customisable filters to patient-generated data views (such as the view in Scenario 3) could support HCPs to focus on, and prioritise, a subset of patients. However, these

filters must be designed with caution to ensure that HCPs do not develop tunnel vision and inadvertently displace attention on patients outside the filtered subset (Dowding et al., 2015). Visual alerts that remind HCPs of the filter that has been applied to their current view could help to avoid tunnel vision.

Previous work has noted that sporadic data entries by patients may be concerning, as it may indicate that a patient is too unwell to monitor their symptoms (Bardram and Frost, 2018; West et al., 2016, 2018). However, West et al. (2018) briefly discussed how some HCPs believed that incomplete data *may not* represent a concern, as it may indicate that patients simply prefer to monitor their symptoms when they feel unwell. My work has concretised how sporadic patient-generated data can be considered clinically acceptable for decision-making around COPD, as long as the patient is consistent with reporting periods of poor health. Sporadic data could therefore still provide use in clinic settings. However, if the patient is unpredictable in how they report data, such as not taking a consistent approach to what they report, this creates a situation where the HCP (and potentially the patient) cannot easily find utility in the data. It is likely that sporadic data may be incompatible with scenarios such as predicting COPD exacerbations, as this would require a higher degree of data completeness and consistency. By the time the patient decides to report that they feel unwell, it may be too late to prevent an exacerbation. A closer focus on how sporadic data might be navigated in clinic settings would enhance knowledge about how this could be supported in practice through design.

4.5.1.4 Trusting Data Sources

There was a clear awareness of the limitations of certain data sources and as a result, HCPs felt distrustful relying on data from certain sources. The coding department and the hospital marker system were two data sources that were cited as unreliable and HCPs were less trustful about relying on them for decision-making. The reliability of coded data has been explored in previous work (Axelrod et al., 2011; Burns et al., 2011; Sunderland, 1985). Particularly around the overlap of clinical codes used to describe a

single clinical condition (Axelrod et al., 2011), which can introduce uncertainty when working with this data. The hospital marker system, which was a system specific to the Hospital and Community Care, had three reasons for why it was perceived as unreliable: (1) it was a poorly utilised feature within the main clinical system which meant the data was not complete; (2) the list was maintained by three different organisations (the Hospital, Community Care, and GP services) which meant some patients were on the list erroneously and had other respiratory conditions; and (3) some patients may be missed from the list due to lack of formal diagnosis[25]. As shown, both the data from the coding department and the hospital marker system contained uncertainty, and this uncertainty led to perceptions of low trust.

As medical data is often bound to the context in which it was originally produced (Berg, 1999), improving the accuracy of data sources requires additional work to be carried out by the HCPs (Berg, 1999; Berg et al., 1998). In the case of the hospital marker system, this requires a more consistent use of the flagging system within and between organisations. Unlike the hospital marker system, coded data is inherently uncertain due to how codes are attributed to health conditions. How we can work towards fixing the coding system is beyond the bounds of this thesis, but it raises the importance of increasing transparency about data sources that are used to facilitate DSDM technologies. Knowles (2016) suggested that an explicit mention of a system's data sources is important for building trustworthy systems. I argue that being explicit about the data sources used for visualisations can help build trustworthy DSDM technologies for healthcare. One way to approach this could be by visually mapping uncertainties on the system's interface. For example, heat maps and icons could be used to represent the degrees of uncertainty in a specific data source that is being used to facilitate visualisations. Simply being clear about the data sources used to facilitate visualisations could help HCPs to better incorporate their local understandings of datasets when interpreting data.

[25] Recall that HCPs discussed the challenge of COPD misdiagnosis in section 4.4.2.2 (pg. 99).

4.5.2 Integrating Systems into Workflow

This study raised important practical challenges, particularly in relation to the eventual deployment of a DSDM technology into clinical practice. Previous studies have shown the considerations that need to be made when deploying technology into clinical contexts (Ackerman et al., 2017; Hansen et al., 2006; Zhou et al., 2009). For example, considering who will maintain the system from a technical perspective (Hansen et al., 2006), how the integration of the system should occur (Ackerman et al., 2017), where the system will physically be placed and how this impacts work (Zhou et al., 2009). I consider these practical questions to be important to the overall discussion on the role of DSDM in healthcare, in order to move from theoretical thinking to considering pragmatics. Though the prototype in this study was not deployed in clinical practice, I have gained insights into potential challenges which surround the deployment of DSDM technologies. In the sections below, I discuss two main points: 'actions and protocols' and 'training on systems'.

4.5.2.1 Actions and Protocols

Agreeing sufficient protocols that specify what actions can be taken in response to the prototype's data was raised as an important consideration. Recall that when discussing data priorities in Stage 2 (Priorities and Implementation Challenges), one HCP stated that there is a requirement to form *"agreements with other Trusts about how we respond to these spikes in admissions"* (H3, section 4.4.2.1, pg. 98). For some scenarios, HCPs highlighted that new organisational arrangements would be necessary to effectively make use of the insights. This was raised regarding two areas specifically. The first area is about planning and organising resources to deal with service demand that may be visualised on the prototype (i.e. simply *knowing* that there is a spike in admissions is not adequate, HCPs should be able to react to this data sufficiently). The second is about responding to remotely received patient-generated data (e.g. what are HCPs obligated to investigate when viewing this data).

Both of these areas introduced the HCPs to data which they previously did not have access to, presenting opportunities for the new information to inform decision-making. However, there were no existing organisational protocols that outlined how they should respond to this type of data. One major concern raised by C6 related to the potential lengthy process of 'chasing' patients who were not recording any data in Scenario 3 (Patient-Generated Data Overview). They felt they had an obligation to investigate the reasons why this may be the case, yet there was a lack of guidance on how to do so (or when this would be appropriate to investigate). This highlighted the importance of ensuring relevant (cross-)organisational protocols are in place to ensure HCPs can effectively use DSDM technologies in practice. However, as the DSDM technology becomes part of the wider sociotechnical system within the healthcare organisation (Ackerman et al., 2017), its introduction will have impacts on the existing organisational and social practices of how clinical work is carried out (whether intended or unintended) (Dowding et al., 2015).

The challenges involved in introducing technologies into clinical practice has been observed in previous healthcare research (Ackerman et al., 2017; Bardram and Frost, 2018; Berg, 1999; Cai et al., 2019; Dowding et al., 2015; Heath and Luff, 1996; Pine and Mazmanian, 2014; Tentori et al., 2012). Specific to the concept of actions and protocols, Bardram and Frost (2018) discussed how the deployment of a system for HCPs to remotely monitor patients with bipolar disorder required protocols to govern how the system would be used in practice (including which HCPs would be involved in, and responsible for, which parts of the process). Whereas Cai et al. (2019) noted the legal concerns that pathologists raised in relation to using an artificial intelligence assistant to support prostate cancer diagnosis. They discussed how these legal concerns would ultimately influence whether the assistant would be adopted in practice. These studies serve to demonstrate how the wider sociotechnical implications of introducing new technology into healthcare require careful consideration. As uncovered by my research, introducing relevant protocols to govern how to respond to data should be considered prior to system deployment. This could influence how willing HCPs are to engage a technology, but could also ensure that the intended ben-

efits of the DSDM technology can be properly realised in practice. This is particularly relevant in situations where technologies are evaluated in practice, without supporting HCPs to react to data appropriately then the evaluation metrics about the impact of the technology are subsequently effected.

Both Reddy et al. (2003) and Ackerman et al. (2017) have suggested that understanding the impacts of introducing new technology into clinical practice can be estimated, to some degree, through sociotechnical requirements analysis within the design process. This can be achieved through actively seeking to understand the complex work environments in which medical work is carried out, for example by using ethnographic techniques within the research (Reddy et al., 2003). In addition to using observational approaches in the research, I stress the importance of adopting a multi-stakeholder approach to gain insight into potential sociotechnical implications of technology introduction. Including a diverse stakeholder group can help to bring together a unique blend of expertise that can help map out potential challenges[26] to the clinical and business workflows. In addition to working with diverse stakeholder groups to estimate potential sociotechnical challenges, including diverse stakeholder groups may help to scope any potential protocols which need to be created to govern the use of the technology, as described previously. For example, if organisational or policy changes are required, including senior staff across the organisation can help to consider these possibilities. In some cases this can be a complex process, as depending on the nature of technology being introduced, changes to clinical pathways and guidelines may be required (Bardram and Frost, 2018).

[26]It is important to acknowledge that any practical challenges that may occur due to the introduction of a technology cannot be completely foreseen. However, this exercise can help to identify more apparent challenges.

4.5.2.2 Training on Systems

The time and effort required to train HCPs on new systems was identified as a major challenge during this study. System training was not only identified as time-consuming, but unnecessary by some HCPs who often thought they had the knowledge to quickly master the use of new tools themselves. Despite efforts to train staff, IT staff reported that these challenges led to HCPs using systems that they had not been formally trained on (section 4.4.2.1, pg. 197). In some cases, this had reportedly led to errors in data and disruptions to the workflow. Previous work has noted how a lack of training can inhibit HCPs from supporting technology interventions (Chung et al., 2015; Sarcevic et al., 2018; Thieme et al., 2016; West et al., 2016), or even give rise to unintended and potentially negative consequences of using a system (Dowding et al., 2015; Kim et al., 2017). For example, Sarcevic et al. (2018) designed a dashboard for improving team awareness in time-critical trauma resuscitation units. They highlighted that a key barrier to adoption was around how HCPs could safely use the system, in terms of how the data is found within the dashboard and subsequently interpreted for use. Similarly, West et al. (2016) reviewed research about using patient-generated data in clinical practice and found that HCPs had concerns about being adequately trained to interpret unfamiliar data provided by patients. These studies demonstrates how a lack of training on clinical systems can be a barrier for engaging with data and adopting technologies, and therefore becomes a relevant problem for HCI research.

The barriers around training have direct implications for the deployment of DSDM technologies in healthcare contexts for two main reasons. First, HCPs will need some form of standard training if the system becomes deployed to understand its purpose and how it is used. But second, and more specific to the nature of DSDM technologies, is how the collation of (possibly unfamiliar) data in new ways will require HCPs to effectively interpret and understand this information for decision-making. As described by one HCP, the collation of large datasets can seem *"frightening"* (C8, section 4.4.6.2, pg. 117). The lack of digital skills training among HCPs has been highlighted in previous work (Steen and Mao, 2016), and this remains a challenge

that can effect if, and how, HCPs engage with DSDM technologies. If HCPs are not trained to accurately interpret data on DSDM technologies, they may draw wrong inferences from it, or lack the confidence to use the technology all together as they cannot generate insights (Ackerman et al., 2017).

This echoes findings by Dowding et al. (2017), who conducted a survey study to to assess nurses' numeracy and graph literacy to understand how this may influence data visualisation on dashboards. They discussed that nurses with low numeracy may have difficulties interpreting visual information, and suggested that HCPs with different numeracy and graph literacy may benefit from simple data visualisation techniques (such as bar graphs and tables). This raises important considerations about the potentially different levels of data literacy among different HCP groups. One way that design can accommodate different levels of data literacy is through supporting alternative views of the same data (e.g. by offering multiple different visualisation options according to the users' preference). However, data visualisation options must be designed with caution to avoid creating visualisations that present data in a potentially misleading way (Szafir, 2018). In addition to supporting alternative views of data, when data is collated from multiple sources into a single visualisation[27], dashboards could offer functionality that allows the user to 'select' and 'deselect' data items to avoid overwhelming the user. This could support the user to build an understanding of the complete visualisation at their own pace. However, reminders and alerts would need to be put in place to avoid users forgetting about data items they have deselected so that they do not displace this data.

In terms of training HCPs to use DSDM technologies more generally, flexible scenario-based training programmes could provide ways to build confidence in navigating the system and interpreting the data. However, a stronger understanding of how to support HCPs in effectively interpreting and understanding data on DSDM

[27]For example, in Scenario 2 visualisations had collated exacerbation data from the Hospital, Community Care, and GP practices.

technologies is needed. Until then, it remains a notable challenge to consider when deploying such technology.

4.5.3 Reflections on Evaluation Approach

The research in this chapter concluded with an evaluation of the scenario-based prototype of a DSDM technology. There are important elements of the evaluation stage to reflect on, which can provide valuable lessons about the evaluation of digital health technologies. Though there are numerous HCI technology evaluation techniques (Barkhuus and Rode, 2007), this section focuses on the approach taken in this chapter. In the following two sections about 'using TAM in healthcare technology evaluation' and 'scenario-based evaluation approach', I discuss the advantages and limitations of the evaluation techniques used within this study. I argue that this section presents valuable insights about my chosen methods that can inform future work about evaluating DSDM technologies in the healthcare space.

4.5.3.1 Using TAM in Healthcare Technology Evaluation

TAM has been used extensively in healthcare research to predict acceptance of a variety of digital health technologies (Holden and Karsh, 2010), including telemedicine (Hu et al., 1999), logistic information systems (Tung et al., 2008), and hospital information systems (Nadri et al., 2018). Extended models of TAM have also been used in healthcare research to establish further determinants that can impact technology acceptance (i.e. considering how factors such as 'facilitating conditions' or 'social influence' can influence technology acceptance) (Holden and Karsh, 2010). In short, TAM has been used widely within healthcare research as a way to theoretically predict the acceptance of a range of technologies. However, for this study, adapting the TAM questionnaire to apply it to context of DSDM technologies was challenging. This challenge stemmed from attempting to adapt one of the central TAM variables, 'per-

ceived usefulness'[28] to meaningfully apply to DSDM technologies aimed at supporting clinical decision-making.

I adapted the TAM questionnaire provided by Davis and Venkatesh (1995) with Professor Pearson for this study, which was originally used to evaluate a word processing software. As I adapted questionnaire, Professor Pearson advised how notions of 'improving job performance', 'increasing productivity', and 'increasing effectiveness' — which were included in the original questionnaire — did not align with the aims of clinical decision-making. It may appear that this can be easily explained by the fact I was adapting a questionnaire that was designed for a different technology and context, but similar wording has been used in many previous TAM healthcare studies[29] (Holden and Karsh, 2010). This terminology is unsuited to clinical decision-making, as it is difficult to draw clear inferences about the relationship between how a medical device is designed and how this impacts clinical outcomes (Sharples et al., 2012). Sharples et al. (2012) discussed how medical devices tend to be used in combination with other devices, with multiple actors, within complex situations, which all influences how a task or procedure is completed. Similarly, it may take some time before the effects of a clinical decision can be appropriately assessed. This is directly relevant to how evaluations of DSDM technologies are framed, as technology is likely to be only one instrument within the process of reaching an intended clinical outcome. Therefore, attributing a DSDM technology to improving the 'effectiveness', 'productivity', and 'performance' of the HCP is ill-suited.

For the reasons above, associating 'device' (in this case the DSDM prototype) directly with 'outcome' (in this case the outcome of clinical decisions) was something I avoided when framing the TAM questionnaire. Firstly, as discussed, it presumed the

[28]Defined by Davis et al. (1989) as 'the prospective user's subjective probability that using a specific application system will increase his or her job performance within an organizational context'.

[29]In some studies reviewed by Holden and Karsh (2010), the *exact same* wording has been used in healthcare TAM questionnaires as in Davis and Venkatesh (1995).

outcomes of medical work are immediately evident, measurable, and can easily be detached from their complexities and attributed to the DSDM technology. Secondly, by focusing on influences on 'effectiveness', 'productivity', and 'performance' as a primary measure, the DSDM technology is consequently framed as some form of production means in the Marxist sense (Marx, 1959; Rosenberg, 1974). This suggests the ultimate purpose of the DSDM technology is to enable HCPs to become more time-efficient and economically valuable workers. This largely ignores the complex nature of clinical work, placing a disproportionate emphasis on maximising performance and saving time. As a result of this, during the adaption of the TAM questionnaire the words 'productivity' and 'performance' were excluded. The term 'effectiveness' was used only to describe how the prototype *may* contribute in the delivery of more effective patient care *overall*[30] (acknowledging its part contribution in this process).

The clinical expertise of Professor Pearson helped to ensure that the terminology in the questionnaire was meaningful for clinical contexts. My pursuit to make the TAM questionnaire more meaningful to this study's context follows on from Holden and Karsh (2010)'s call for researchers to better contextualise TAM to healthcare to understand its power. When using TAM in healthcare research, the terminology used in the questionnaire must be carefully considered in relation to the context of study. Particularly, how the terminology aligns with the *value* that the technology intends to bring to the users themselves (rather than how the technology can make the *users* more valuable). Additionally, publishing contextualised TAM questionnaire templates (along with the studies they were used for) helps to build a corpus of valuable questionnaire templates that are relevant to a variety of clinical contexts for future research[31]. Indeed, this could apply to other types of user experience questionnaires issued within healthcare research studies outside of TAM specifically.

[30]The exact ranking statement was 'using Respire may lead to more effective patient care overall'. Respire was the name given to the prototype.

[31]I have included the TAM questionnaire template for this study in Appendix G.

4.5.3.2 Scenario-Based Evaluation Approach

Traditionally the gold standard approach for evaluating the effectiveness of healthcare technologies has been through randomised control trials (RCTs) (Kaplan, 2001b). For example, RCTs have been used to evaluate clinical decision-support systems (Bennett and Glasziou, 2003) and clinical dashboards (Linder et al., 2010). While RCTs are effective in demonstrating factors such as calculating a system's accuracy, they are less suited to assess factors that explain *why* a system is (or is not) used in practice by users (Heathfield, 2001; Kaplan, 2001a,b). This is where qualitative evaluation approaches are valuable and can complement RCT studies (Kaplan and Maxwell, 2005). Through the user-centred and scenario-based approach taken in this research, I was able to discover a number of important factors relating to how DSDM technologies can be designed and deployed for healthcare contexts. Specifically, the scenario-based evaluation allowed participants to envisage important social, cultural, and political concerns surrounding the use of the DSDM prototype.

Through creating realistic dummy datasets with a biostatistician, I resourcefully avoided the need to use real-world healthcare data to facilitate a meaningful early evaluation. Kaplan and Maxwell (2005) have highlighted the importance of uncovering sociotechnical factors during healthcare technology evaluations, as they influence system acceptance and actual use. While I do not argue that the approach taken in this research resembles a formal evaluation process in the same sense as RCTs, it has provided rich insights into potential criteria impacting use, disuse, and misuse of DSDM technologies for respiratory care. Scenario-based approaches and Wizard of Oz approaches have been used throughout HCI research to simulate interactive systems as a way to accumulate early feedback at a relatively low cost (Bardram, 2000; Favela et al., 2010; Stiemerling et al., 1998; Weiss et al., 2009). These approaches can be especially valuable for evaluating DSDM technologies for healthcare, as they provide an early way to identify potential challenges relating to data before the creation of a fully functioning system.

4.6 Study Limitations and Reflections

There are two important limitations arising from this study. The first limitation relates to the findings from Stage 4 (Evaluation). Stage 4 consisted of the same HCPs who informed the design of the prototype (with the exception of H5). Involving the same HCPs in the design and evaluation of the prototype could have introduced positive bias into the feedback, with participants potentially responding more positively to the prototype as they were involved in its design (i.e. the 'IKEA effect' (Ceil, 2019; Norton et al., 2012)). I attempted to mitigate this potential bias by activelh trying to recruit additional HCPs for the evaluation. However, I unsuccessful due to the challenges in recruiting this participant group (I reflected on this in the methodology: Chapter 3, section 3.5.2, pg. 57). I could only recruit one new HCP (participant H5). Though I acknowledge there may be bias present in the evaluation results, I argue there were important benefits to retaining the same HCPs throughout the entire process. Many of the important findings arising from this chapter have related to the sensitive topic of trust in the workplace, and I believe the familiarity built between myself and the HCPs facilitated the unpacking of this delicate topic. Likewise, involving the same HCPs throughout the process introduced consistency across each of the different stages. However, it is still important to interpret the evaluation findings with caution to account for any potential bias.

Finally, this research was undertaken with multiple HCPs from two NHS organisations in the north west of England. The local context and ways of working of both organisations has shaped the findings within this chapter. As a result, this limits the degree of generalisability across other healthcare contexts. Different healthcare organisations across the world will have their own organisational structure, resource constraints, and individual clinical pressures. That is not to say these research findings cannot transfer outside of this study's contextual confines, rather, I acknowledge that these findings are not representative of all respiratory healthcare services. Therefore, when interpreting the findings of this work, it is important that the reader considers how these findings may resonate or differ across healthcare settings.

4.7 Chapter Summary

This chapter explored how DSDM technologies could support HCPs in their decision-making abound COPD care. Through documenting the design and evaluation of a DSDM prototype that aimed to support decision-making about COPD, I uncovered the challenges and opportunities for DSDM technologies to support HCPs in this space. The study was carried out in four stages with 17 participants, involving the expertise of different stakeholders at each point. First, I sought to understand the motivations for a dashboard, challenges with the current clinical systems, and discuss initial data needs. The second stage involved learning about the different existing clinical systems, outlining and prioritising data needs for the dashboard, and identifying any potential feasibility barriers for acquiring this data. The third stage involved working iteratively with HCPs to create wireframes that incorporated their data needs, before focusing on a subset of scenarios to include in the digital prototype. The fourth and final stage involved qualitatively evaluating the prototype with HCPs to explore how they envisaged it could support their decision-making in practice.

The findings highlighted important considerations for designing and deploying DSDM technologies for respiratory care. This includes: the concept of trusting data for clinical decision-making and how this depends on the data source and author; how to support integrating systems into workflows by considering how HCPs can be trained on systems and respond to data in practice; and finally reflections on evaluating DSDM technologies for healthcare settings. These findings take us a step further to understanding how DSDM technologies could support HCPs in practice.

The next chapter explores a different perspective: the rich lived experiences of COPD. It explores how technology can support the lived experience of COPD by engaging the wider chronic respiratory community through a survey, interviews, and a workshop. This complements the research presented in this chapter, offering the experiences of COPD from the perspective of those who live with the condition.

Chapter 5

The Role of Technology in Supporting the Lived Experience of Chronic Respiratory Conditions

Some of the data and findings from this chapter have been published as a full paper in the 2019 EAI International Conference on Pervasive Computing Technologies for Healthcare (*Tendedez et al., 2019b*).

5.1 Introduction

This chapter explores the lived experiences of chronic respiratory conditions (CRCs) and the potential role of technology to support this experience. This chapter mainly focuses on experiences of self-management and self-care of Chronic Obstructive Pulmonary Disease (COPD). Practices of self-care and self-management are collaborative in nature (Nunes and Fitzpatrick, 2015), often involving patients, healthcare professionals (HCPs), and carers. However, for the purposes of this study I focus on the perspectives of the person with the respiratory condition. I have chosen to do this to

build a rich understanding of the embodied experience of living with a CRC to gain a first-hand understanding about if, and how, technology could offer support.

To achieve the aims of this chapter, I present findings from a survey of 147 respondents, one-to-one interviews with 13 participants, and workshop findings with 11 participants. I present detailed and nuanced findings about the lived experiences of CRCs, and demonstrate the opportunities and limitations that technology could have for supporting this experience. I take an open-ended approach to consider different types of technology. This chapter aims to answer the second research question: 'what is the lived experience of COPD, and how can technology support this experience?'

The key contributions of this chapter can be summarised as follows:

1. Some participants take a 'reactive' approach to managing their condition, which could influence how they choose to engage with technologies for self-management.
2. Participants described how their condition needs evolved over time. Needs changed in two ways: (1) as they developed experiential experience of living with the condition and (2) as the condition naturally progressed. However, a common need when starting the condition journey is adequate information at diagnosis.
3. Some people with COPD may require additional support and encouragement for seeking help for their condition, as they experience stigma about their condition and concerns about 'burdening' support networks.
4. As COPD is linked to social deprivation and an older adult population, there is a strong need for researchers and designers to actively and carefully consider the accessibility and inclusively of the digital support that they create.

5.2 Study Design and Methods

This chapter reports on a three stage study involving the CRC community. The majority of participants had COPD. However, as discussed in Chapter 2 (Background and Related Work), there is diagnostic uncertainty involved with COPD and it can overlap with other CRCs (Chapter 2, section 2.1, pg. 15). Therefore, engaging the wider CRC community was an attempt to be considerate of these challenges and include a wider perspective. The first stage of the study involved a survey to gather a broad understanding of the CRC community's experiences of self-care, experiences using technology, and their perceptions on using technology for the self-management of their condition(s). The second stage involved conducting one-to-one interviews to explore the lived experiences of having a CRC and experiences of using self-management technologies in richer detail. The interviews allowed me to uncover and explore insights in greater depth, which was not possible through a survey alone. The third and final stage involved a workshop with a respiratory support group to further expand on the insights from interviews. All participants were provided with an information sheet and consent form to consider before study participation (see Appendix I).

5.2.1 Respiratory Support Groups

A vital part of this study was my engagements with three respiratory support groups in North West England (described in Chapter 1, section 1.2.2, pg. 7). There are over 230 of these Breathe Easy groups across the United Kingdom (UK)[1]. The groups are self-organising and meet at different intervals, for example, some groups meet once a week and some once a month. Group members are people within the respiratory

[1]At the time of publishing this thesis, The British Lung Foundation reports that there are over 230 Breathe Easy groups across the UK: https://www.blf.org.uk/support-for-you/breathe-easy (accessed July 9th, 2020).

community, including family and friends. During group meet ups, they may have visitors who give health talks (such as healthcare professionals (HCPs) who share health information or advertise clinical research studies); talks about government support (such as disability and carers' allowance); teach lightweight exercise classes (promoting breathing techniques and an active lifestyle inline with their condition); and singing classes (which can help symptoms and improve general wellbeing). The group also carry out more general social activities such as quizzes and raffles.

Figure 5.1: A picture of me presenting my research at one of the support groups.

To better understand and familiarise myself with the CRC community, I spent 12 hours embedded in three different respiratory support groups in North West England. I did this to prepare for the study, particularly the one-to-one interviews (Figure 5.1). During this time, I observed group discussions about CRC; participated in group exercise activities (such as armchair exercises and tai chi); participated in social activities at the group more generally; and shared my research aims with them. The groups were very welcoming with me, and appeared interested in helping me with my research. I kept in close contact with two out of the three groups over the course of the research due to their closer proximity to Lancaster University (where I was located). I was

invited to join one group's closed Facebook group where they shared group related information, such as: summaries of the meetings; updates on members' health; sharing of photos; and the organisation of any upcoming events. The lead for the other group would email me their monthly e-newsletters and kept in written contact with me over the course of the study. As such, in between my visits to the group, I was updated about the groups' activities.

5.2.2 Survey

The first stage of data collection was a survey. The survey, hosted on Qualtrics, consisted of 17 core questions, ranging from free-text responses to selection lists for user input. It was open for 70 days, and was advertised primarily through a snowball sampling approach (Johnson, 2014). I distributed the survey link through email and social networking websites (Facebook, Reddit, and HealthUnlocked). I used the COPD community forums on HealthUnlocked and Reddit as a way to reach people with CRCs to participate. I also sent paper versions of the survey to four respiratory support groups[2] in the UK (who then distributed these to their members and posted responses back to me), to reduce the chance of technology literacy bias in the results and to ensure the responses reflected both online and offline communities. A full list of the survey questions is included in Appendix J.

Once the survey had closed, responses were collated and analysed using NVivo software to better organise, manage, and code the number of survey responses (Welsh, 2002). Details about how I conducted analysis of the survey responses is included in Chapter 3 (Methodology, section 3.3, pg. 49).

[2]Three of which I had been visiting to prepare for this study, as described in the previous section.

5.2.3 Interviews

The second stage of the study involved 13 one-to-one semi-structured interviews with people with CRCs. Most participants were recruited through the support groups, but interview recruitment was also advertised online (on Lancaster University's website and social networking sites) and through a patient and public involvement lead. I set out to recruit participants that varied in their age, length of time having been diagnosed with a CRC, and their experience of using self-management technology for their condition. This would help to ensure that diverse and rich perspectives were captured. Table 5.1 outlines details of the 13 interview participants.

Participant	Age	Gender	Condition	Diagnosed
Nelly*	63	Woman	COPD and Asthma	14 years
Irma	65	Woman	COPD	1.5 years
Jin	67	Man	COPD	5 months
Amy*	80	Woman	COPD and Asthma	50 years
Joti	58	Woman	Asthma	43 years
Hedge	69	Man	COPD	20 years
Fred	83	Man	COPD	5 years
Dan*	82	Man	COPD and Asthma	5 years
Seb	66	Man	COPD and Asthma	10 years
Mary*	50	Woman	COPD and Asthma	3 years
Maggie	74	Woman	COPD and Asthma	8 years
Tina*	60	Woman	COPD and Asthma	4 years
Ken	66	Man	COPD	6 years

Participants denoted with an asterisk (*) were not recruited from support groups and had no involvement with support groups.

Table 5.1: Chapter 5 interview participants and their assigned pseudonyms.

Before finalising the interview schedule, which would be used to guide the interviews, I provided the proposed schedule to an experienced patient and public

involvement lead, Debbie Parkinson, who provided feedback on the questions. Debbie Parkinson also provided the interview schedule to a COPD patient champion whom she worked with, who additionally provided feedback on the wording of the questions. It was important to me to gain feedback on the questions so I could ensure that my language and the wording of the questions were sensitive and inclusive. Interviews were then conducted using a semi-structured exploratory approach, which allowed the questions to change direction (to an extent) to explore interesting ideas and insights discussed by participants.

Interviews lasted between 30 and 60 minutes and were held at a location local to participants to account for any mobility challenges. For example, interviews were held in local libraries, cafes, the venue of their support group, or their homes. During the interviews, participants were asked to recall their experiences of diagnosis, daily challenges they experienced, how they self-managed, and experiences using technology (for CRC self-management or otherwise). They were then asked if they believed technology had the potential to support their self-care practices. Participants were welcome to bring a family member or carer with them to the interview to accompany them, though only one chose to do so (Fred, who brought his wife). Details about how the interview data was analysed is provided in Chapter 3 (Methodology, section 3.3, pg. 49).

5.2.4 Workshop

The third and final stage of the study was a workshop held at one of the support groups that I had been engaging with. The aim of the workshop was to explore two of the key findings from the interviews in more detail, through detailed discussions with the respiratory community. These two key themes were (1) the lack of information from healthcare services, and (2) the value of support networks (a detailed account of the full findings from the interview stage are in section 5.4). The support groups were a great avenue to explore the wealth of experience and knowledge that members had in these areas.

To organise the workshop, I approached the group lead and proposed a workshop plan. The group lead discussed the plan with the members, who then informed me that they would like to participate. The workshop lasted 90 minutes and was held during one of their regular meet up slots. There were 11 participants (six women, five men) aged between 43 and 81 (see Table 5.2). As there were two areas I wanted to explore (information needs and support networks), I allocated 30 minutes for discussions on each (with the remaining time spent on the consent process, handing out material, and breaks). I had assistance with running the workshops from Dr Roisin McNaney and Dr Stephen Forshaw who, alongside me, sat with participants in their groups during the workshop activities to probe discussions and answer any questions. At the start of the session, I divided participants into two groups to manage the discussions. The idea was that participants could have smaller discussions in their groups, and then reconvene to present and discuss ideas together after each activity. This would give all participants the chance to be heard in their groups.

Participant	Age	Gender	Condition	Group
Elliot	69	Man	Bronchiectasis	Two
Rose	66	Woman	COPD	Two
Max	80	Man	COPD	One
Tony	74	Man	COPD	One
Lisa	74	Woman	COPD and Asthma	Two
George	68	Man	Carer	One
May	81	Woman	COPD	One
Daisy	43	Woman	COPD	One
Linda	82	Woman	COPD	Two
Eva	74	Woman	COPD	Two
Daryl	79	Man	Asthma	Two

Note that workshop participants discussed the uncertainty around their respiratory diagnoses. Therefore, the data within the 'condition' column represents their formal diagnosis at the time of the workshop.

Table 5.2: Chapter 5 workshop participants, their assigned pseudonyms, and groups.

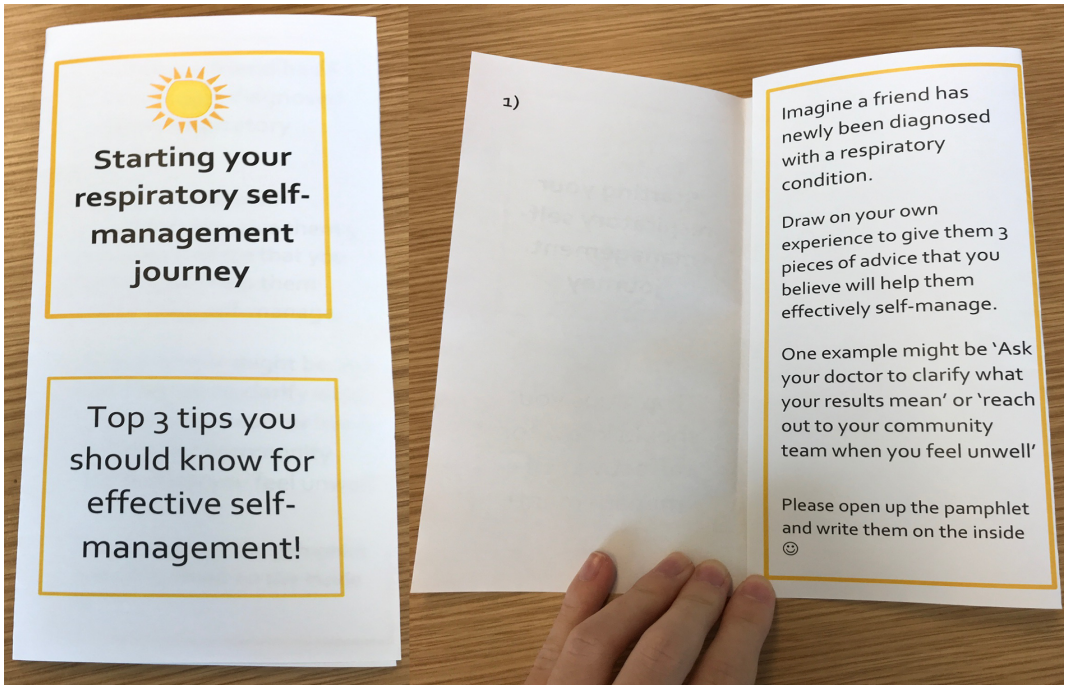


Figure 5.2: A picture of the mock pamphlet used to stimulate discussion around information needs.

To prepare for the discussions around information seeking, I designed an activity to help participants structure their experiences and information needs, as if they were advising a person newly diagnosed with COPD. To do this, I created a mock pamphlet (Figure 5.2) which asked participants to list three of their top self-management tips that they believed would help somebody start their journey with COPD. I advised participants not just to think about practical tips about managing their condition, but also tips that could help people manage emotionally and mentally. Participants were welcome to discuss their ideas with their group, but were asked to think of three individual things by themselves first to ensure that different perspectives were explored. After they had written their three pieces of advice, they were asked to discuss their ideas as a group and agree on three of the most important pieces of advice. The two groups then joined to discuss one another's advice emphasising its importance. Figure 5.3 shows participants engaged in the activity.

Figure 5.3: A picture of the discussions with workshop participants.

The second part of the workshop was focused on discovering what support networks participants relied on as part of living with their condition. Participants were asked in their two groups to discuss the different support channels they would use on a day during which they felt 'not so good' either physically or emotionally. I tried to avoid using the term 'bad day' to initially describe the activity as I did not want participants to reflect too negatively on their condition. However, during the activity, participants used the term 'bad day' themselves, which then normalised the use of the term during the workshop. The purpose of this activity was to explore the support participants felt they required to manage their condition, and where they seek this support. I gave participants the option to note their feelings on different types of

days (good day, normal day, bad day) on a small sheet of card. However, the cards were not heavily used during the activity and instead participants preferred to verbally discuss their ideas in the group. At the end of the activity, I asked both groups to jointly discuss their ideas out loud while I made notes.

5.3 Survey Findings

147 responses were gathered from the survey. Of these, 114 were online responses and 33 were paper. Within the 147 responses, 98 self-identified as women, 47 self-identified as men, and two self-identified in another way. In terms of length of time having lived with a CRC, 58% of respondents had lived with their condition for 10 or more years, 13% for six to nine years, and 29% for five years or less. This means that most respondents had lived with their CRC for a relatively long time. The breakdown of respondents by age is shown in Figure 5.4, location in Figure 5.5, and CRC in Figure 5.6. Where free-text responses are discussed, respondents are referred to as R*n*, with *n* representing the respondent's identifier (e.g. R5 represents respondent 5).

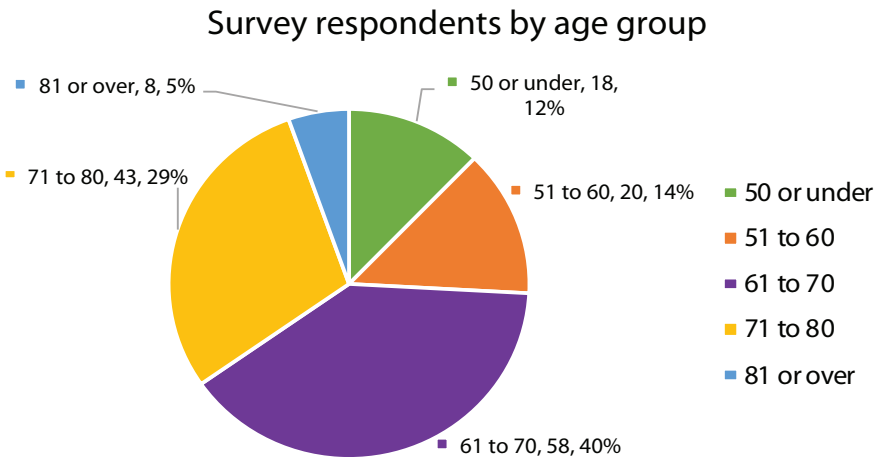


Figure 5.4: Survey respondents by age group.

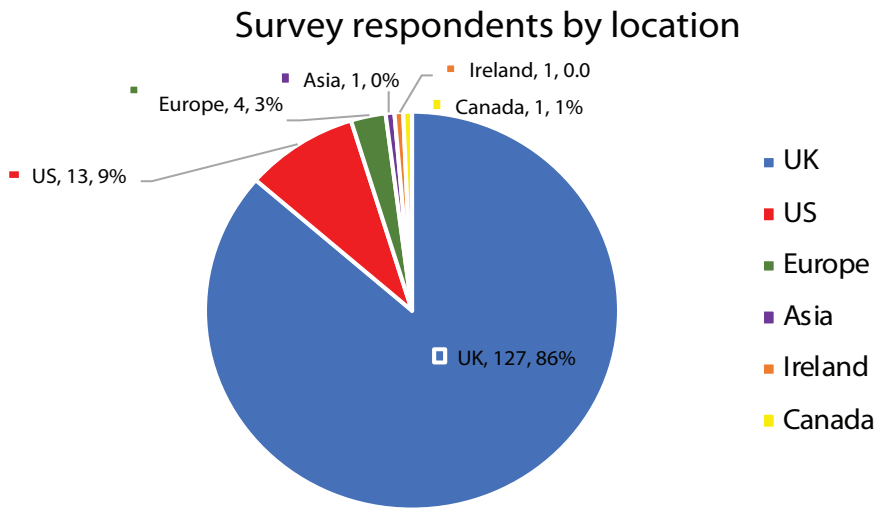
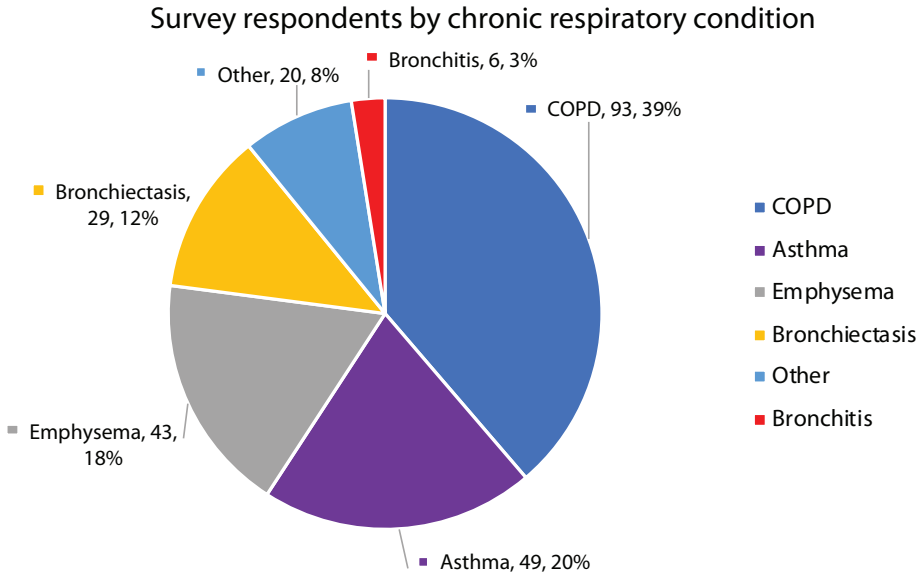


Figure 5.5: Survey respondents by location.

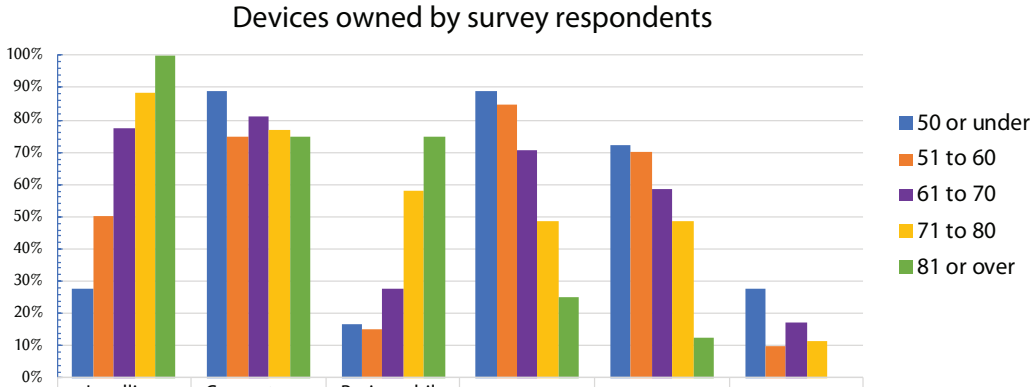


Note: respondents could select that they had more than one CRC.

Figure 5.6: Survey respondents by chronic respiratory condition.

5.3.1 Device Ownership and Usage

Respondents were asked to select all the devices which they owned from a list that included: 'landline telephone', 'computer or laptop', 'basic mobile phone', 'smartphone', 'tablet', 'smartwatches', and 'games consoles'. The aim was to understand the types of mainstream devices which respondents owned and engaged with, to understand the everyday device usage across the community. In decreasing order of ownership across the survey dataset, results were as follows: computers and laptops (80%, 117), landline telephone (72%, 106), smartphone (66%, 97), tablet (56%, 83), basic mobile phone (36%, 53), smartwatches (15%, 22), and games consoles (10%, 14). All respondents (100%, 147) owned at least one of the listed devices. Figure 5.7 shows the break down between device ownership and age across all device categories.



	Landline telephone	Computer or laptop	Basic mobile phone	Smartphone	Tablet	Smartwatches
50 or under	27.78%	88.89%	16.67%	88.89%	72.22%	27.78%
51 to 60	50.00%	75.00%	15.00%	85.00%	70.00%	10.00%
61 to 70	77.59%	81.03%	27.59%	70.69%	58.62%	17.24%
71 to 80	88.37%	76.74%	58.14%	48.84%	48.84%	11.63%
81 or over	100.00%	75.00%	75.00%	25.00%	12.50%	0.00%

Figure 5.7: Devices owned by survey respondents broken down by age group.

The most commonly owned device across the entire dataset was a computer or laptop (80%, 117) and the least commonly owned device was a smartwatch (15%,

22). With the exception of computers and laptops, newer devices were increasingly owned by younger respondents. For example, though smartwatches were the least commonly owned device generally, they were mostly owned by respondents aged 50 or under (with no respondents aged 81 or over owning a smartwatch). Likewise, landline telephones were owned by 100% of respondents aged 81 or over (with only 28% of respondents aged 50 or under owning landline telephones).

96% (141) of respondents answered that they used 'smartphones', 'computer or laptop', and 'tablets' for: browsing the internet (89%, 126), sending and receiving email (89%, 126), messaging family and friends (87%, 122), shopping online (84%, 119), social networking (62%, 88), and playing games (52%, 73). Computers and laptops were the most used device to undertake each of these activities, except messaging friends and family, where smartphones were more commonly used for this purpose.

5.3.2 Self-Management Experiences

Respondents were asked to select the types of techniques and methods they had used (either currently or in the past) to manage the symptoms of their condition (Figure 5.8). 'Taking prescribed medication' (96%, 141), 'pulse oximeter readings' (49%, 72), and 'following exercise plans' (48%, 71) were the most popular techniques that respondents had tried. 'Keeping a diary of symptoms and reflecting' was the least popular technique (13%, 19). Respondents that selected 'other' techniques were asked to specify and noted techniques such as: *'positive thinking and avoiding conditions that may lead to infection'* (R62), *'being a member of the British Lung Foundation [a respiratory support charity]'* (R109), *'[visiting] British Lung Foundation, HealthUnlocked and Public Health Agency website[s]'* (R32), and *'[practicing] meditation and wellbeing'* (R40).

In terms of technology used for managing CRCs, 61% (91) of respondents reported having experience of using technology for self-management either currently or

in the past. Of those who had used technology for self-management, 56% had taken pulse oximeter readings, 14% had used a dedicated mobile health app for their CRC, 12% had used wearable technology such as smartwatches, and 10% had used other types of technology to manage their CRC. For example, respondents mentioned using telemonitoring, digital spirometers, peak flow meters, and researching information about their condition on the Internet.

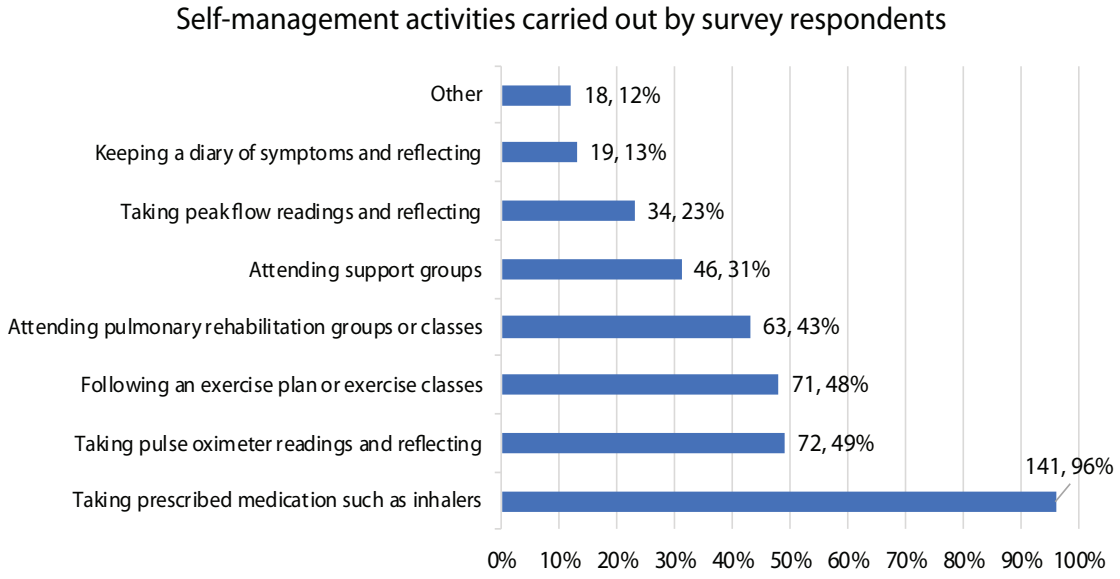


Figure 5.8: Self-management activities carried out by survey respondents.

5.3.3 Challenges Living with CRCs

The following sections detail the two most prominent themes from the free-text responses to the question 'what is the biggest challenge that you face living with your respiratory condition(s)?' The themes relate to physical challenges and mental challenges faced by respondents in their everyday lives.

5.3.3.1 Mobility, Fatigue, and Breathlessness

Mobility, fatigue, and breathlessness were listed as the most challenging aspects of living with a CRC in the survey dataset. Combined, these factors were referenced by 60% (88 times) of respondents in the question around the biggest challenges that respondents faced living with their CRC. Mobility, fatigue, and breathlessness are all interwoven and had significant and *'debilitating'* (R61) effects on the everyday life of respondents. For example, they effected R9's ability to *'complete household chores, socialise, or provide childcare'* and led to R32 feeling as though they *'always have to consider if I can do anything if at all'*. Respondents discussed having difficulty doing seemingly *'normal things'* (R87, R126, R96, R63, R38, R16), including *'simple household chores [which] are a major event'* (R63), *'going out on my own'* (R35), *'capacity to care for myself'* (R99), and the feeling that R96 is *'just sitting on sidelines'*. The challenges of conducting day to day activities also impacted the way respondents perceived their life, with many noting that *'there is no 'normal' in my life anymore'* (R83), and not *'being able to breathe well enough to continue leading a 'normal' life'* (R81), not being able to live *'the life I used to lead'* (R21), and generally *'living a normal life'* (R43) as a result of *'not being able to do things I used to do'* (R20) and how the *'goal posts move due to progression [of the condition]'* (R88).

5.3.3.2 Isolation, Depression, and Anxiety

While 45% of respondents had family as social support and 18% had friends as social support, 11% of respondents said that they had no social support at all. This ties in with the themes of mental challenges that emerged as a challenge living with CRC, which was discussed by 18% (26 times) of respondents in the question around the biggest challenges that respondents faced living with their CRC. Leading on from the physical challenges in everyday life noted in the previous section, respondents discussed how isolation, loneliness, and depression had an impact on their lives. For example, the ways in which being *'unable to do simple things can be very isolating'* (R127) and led to respondents *'rarely leave[ing] the house'* (R83) which *'severely limits*

social contact' (R46). In addition to social isolation, some respondents discussed experiencing anxiety and fear about the future and the *'the unknown'* (R68, R111, R112, R138) of living with a progressive chronic condition. One respondent noted that they faced significant challenges *'coming to terms with the effect this illness will have on me and my family in future years'* (R61) while another discussed challenges associated with *'on waking every morning, never knowing what I am going to be able to achieve'* (R82).

5.3.4 Communicating with Healthcare Professionals

The following sections discuss respondents' free-text answers to the question 'how do you currently share details of your symptoms and general wellbeing with your clinician during appointments?'

5.3.4.1 Communicating Symptoms in Clinic

Most respondents (111, 76%) answered that they simply verbally shared their symptoms and level of wellbeing at appointments with their HCPs. Some respondents (29, 20%) mentioned that their verbal narratives revolve around *'any ups and downs'* (R42) in their symptoms over a period of time, or putting their recent clinical test results in context to how their symptoms have been (such as blood tests, chest x-rays, spirometry tests, six minute walk tests[3], or oxygen saturation tests). Respondents mentioned meeting with various types of HCPs to discuss their symptoms and have periodic reviews, including respiratory nurses, COPD specialist nurses, general practice nurses, respiratory consultants, General Practitioners (GPs), and physiotherapists.

[3]Six minute walk tests require patients to walk as far as they can for six minutes to test exercise tolerance.

This is reflective of the multi-disciplinary team approach involved in chronic condition care (Kuzma et al., 2008; Wagner, 2000).

5.3.4.2 Using External Data to Supplement Discussions

There were 22 references (15%) to respondents bringing extra materials into clinic to supplement their verbal discussions about their symptoms. For example, some respondents mentioned bringing in paper and digital diaries to help them recall their symptoms and experiences, written notes on questions which they want to ask the HCP, diaries of pulse oximeter readings and trends, printed information found on the internet about their condition, and mobile health app data. Two respondents expressed how HCPs tend to be *'uninterested'* (R21, R17) in their observations and readings. One respondent felt that diaries *'do not tell the clinicians anything that I could not tell them myself. Basically another thing to add to the daily routine and a waste of time'* (R18).

5.3.5 Summary of Survey Findings

There were a total of five key take-aways from the survey:

1. All respondents owned technology, with younger respondents owning newer devices. Many respondents used their devices to communicate with people and browse the internet.
2. The majority of respondents had used technology to self-manage their CRC, with pulse oximeters being most common device used and wearable technology being the least common.
3. Taking medication is the most common self-management activity, while keeping a diary of symptoms being the least common.

4. CRCs introduce significant physical limitations and uncertainties for the future, which contributes to social and mental health difficulties.
5. Some respondents use external data to support conversations in clinic, which they discuss with a diverse range of HCPs.

5.4 Interview Findings

The survey provided a broad picture of technology use, experiences of self-management techniques and technologies, and communication with HCPs within the respiratory community. However, the 13 interviews offered a deeper and richer understanding of how technology could support self-care interventions and make a meaningful difference to people's quality of life. Some aspects of the interviews expand on topics from the survey, while others uncover a completely new account of people's experiences. Emergent findings are summarised below under the following themes extracted from the thematic analysis: (1) 'building an understanding of chronic respiratory conditions'; (2) 'challenges living with chronic respiratory conditions'; (3) 'management approaches'; and (4) 'experience of self-monitoring technologies'.

5.4.1 Building an Understanding of Chronic Respiratory Conditions

The following sections discuss key findings that relate to the ways in which participants had to build their own understanding of what their CRC was, and how it should be managed. The two key themes within this section are (1) 'lack of information from healthcare services' and (2) 'building confidence through peer support'.

5.4.1.1 Lack of Information from Healthcare Services

All participants discussed not having enough information about their condition at the point of diagnosis, with the exception of Fred. 10 participants described having to do their own research online to learn more about their condition as they had unanswered questions about their diagnosis and how to self-manage. For example, there were concerns over how a diagnosis of COPD impacted existing respiratory conditions, such as asthma. This effected Nelly, Mary, Maggie, and Tina. They discussed how understanding *"where the asthma and where the COPD came in"* (Nelly) could help understand if symptoms would be any different *"if it was just COPD, or just asthma"* (Tina) and *"if there's anything different I need to do to manage"* the two respiratory conditions. For Tina, the only distinction she had regarding her COPD and asthma was the different inhalers she was told to use *"the blue one is for asthma, the pink one and the green one is for COPD, I do them by colours!"* Other participants felt that COPD was only briefly explained to them at diagnosis, if at all, which left them with many questions about how to move forward as they had not heard of the condition before. For example, Seb discussed *"how not one person ever told me anything about it when I was diagnosed. It was just 'that's what you've got, use this inhaler and go"'*, while Mary was not even told *"what it stood for, they just said you had COPD, that was it, that was literally it"*.

Lack of information also led to feelings of fear about participants' future. They discussed how the uncertainty around their prognosis had implications for their life going forward. Some participants felt uncertain about how the condition effected their life expectancy, for example Nelly questioned *"does it mean that my lifespan will be shorter by 10 years?"* Whereas Seb discussed significant impacts on his mental health as he *"thought it was terminal there and then"* and self-research left him *"depressed"* as he uncovered negative stories online from other people living with COPD. The fear associated with not understanding the prognosis and how to avoid exacerbations was highlighted by Jin as being an area which should be better recognised by healthcare services. He summarised this need by stating *"sometimes you get the feeling you're*

out on your own ... they'll [the health service] supply you with the medicine but that's all you're gonna get".

Participants were asked to describe what information they felt would have helped them at diagnosis. Ideas ranged from information *"co-written with people with COPD"* (Mary) to a *"welcome to the world of COPD"* (Hedge) bag which has *"information about drugs [and] how to take inhalers"* (Hedge). The cause of the condition was also mentioned as important to participants, who felt that they were simply asked *"had I smoked"* (Maggie), which was pinpointed as the reason without further investigation. This frustrated participants, especially those who had not been a smoker, or had not been a smoker for many years. They discussed needing further explanation to understand why COPD had developed after so many years, and to *"keep out of that situation [that caused the condition]"* (Ken) in case there were other causes that could exacerbate the condition. Whereas Mary believed that a lack of explanation or further investigation was *"because they [HCPs] held the view that it was our own fault, whether they'd admit that, whether it was conscious or unconscious, because if they had been telling you that you had anything else, I don't think they would have just said that and sent you away"*.

5.4.1.2 Building Confidence through Peer Support

Participants believed peer support helped them in the management of their condition. Peer support contributed to easing anxieties around the future and built confidence in day to day living with a CRC. Participants that attended support groups believed that they were positive avenues to exchange knowledge with others directly effected by the condition. The information obtained from the groups was perceived to be the information that should have been acquired from HCPs at diagnosis. Learning from these peers allowed participants to experiment with new techniques to help them manage their conditions better at home. For example, Fred discussed accessing information through the group that he otherwise would not know about: *"I was talking to an old lady [at the group] and she's got a little fan, she said to me, 'go and buy one*

of these fans and it helps you to breathe"'. Whereas Jin discussed how practical advice obtained through the groups helped limit the need for frequent clinic visits: *"I can't go to the doctor every time I get a little tweak so, [I go to] this group"*.

Moreover, support groups enabled participants to build confidence around living with their condition. Participants discussed how attending support groups made them feel more hopeful about their condition as *"you are not struggling on your own"* (Maggie), a contrast to how they described their feelings when initially diagnosed. Irma believed that this was due to peers having *"lots of experiences and some of them have had the condition for many years"* which meant that people could learn from one another's experiences. Seeing people who were in the later stages of the condition, but were managing effectively, helped Irma to change her outlook about her own future: *"that made me think hang on ... [I can] sit here and let it get hold of me, or I can turn it all around and be positive and try and manage it the best way that I can"*. Whereas Seb described how attending support groups has made him an *"expert"* in COPD, as *"there's not anything I do not know about my lung condition, and inhalers, and how to look after myself, diet, exercise, etc. Breathe Easy [the support group] has taught me all this"*. The support groups also exchanged recommendations on available self-management technologies, where a few members would trial the technology and then feedback to the rest of the group. For example, Ken discussed how two members of the group have *"tried loads of stuff"* and would recommend things to the rest of the group or say *"no that's not worth it"*. For Mary, support groups were perceived as valuable, but *"the majority of support for people with COPD is during the working hours"* which meant they are *"not accessible to people like myself"* as she had a full time job.

Peer support groups additionally helped participants build confidence in asking questions about their condition, such as with HCPs or with one another. Hedge discussed that being proactive is important in obtaining information about his condition, and as such, he would *"would make a list of things that I had to ask the consultant"* which gave him the information he needed *"because I asked the questions"*. Likewise, Fred felt the encouraging atmosphere of support groups gave him the confidence to

be more proactive in interactions with his HCP:

> *"We have the doctors from the hospitals coming [to the group] ... it was a question and answer session ... you can find out things that you wouldn't usually find out ... some people asked questions which then gave you the incentive to ask questions, so if I want to know something now, I would ask."*

The more emotive aspects of living with a chronic condition were thought to be easier to discuss and resolve in support groups compared to in discussions with HCPs. For example, questions such as *"why me? I'm not old enough, I've never smoked"* (Irma) and *"what's going to happen to me in the future?"* (Nelly) were discussed as being difficult to address with HCPs, particularly as they are *"always in too much of a hurry"* (Seb) such that it can be challenging to raise additional questions. However, through meeting people with similar conditions and experiences, participants felt more confident and assured. This emphasises the need for support networks to consist of those with similar conditions, needs or experiences, especially for coming to terms with more emotive aspects of living with a CRC.

5.4.2 Living with a Chronic Respiratory Condition

The following sections discuss the key themes from the interviews around the challenges of living with a CRC. There were three themes which relate to (1) 'physical oppression', (2) 'emotional impact', and (3) 'guilt and stigma'. These themes are unpacked below.

5.4.2.1 Physical Oppression

Participants expressed daily physical challenges of exhaustion and breathlessness, which was described as *"oppressive"* (Nelly) as it affected participants' ability to conduct everyday activities such as household chores, socialising, and leaving their home.

Hedge summarised this challenge by emphasising to me that regardless of having a good or bad day in relation to his condition, everything he does *"is really limited by the COPD."* This led to participants giving up their hobbies or avoiding certain social situations, particularly if either situation triggered a flare up of their condition (such as being around smoke or pets). Amy recalled having to give up her life-long hobby of playing sports despite strong perseverance to continue, as the effects it had on her COPD could not be stopped: *"I lost control of my breath and I couldn't get near an inhaler and I thought 'why am I putting myself through this?' I decided then enough was enough and I finished."* While some participants were able to continue being active, albeit by pacing themselves and reducing activity levels, others felt unable to lead an active lifestyle. Jin discussed how his breathlessness had stopped him from enjoying long walks, which now impacts how often he is willing to leave his house as *"you're wishing you never came out"* due to breathlessness, which *"doesn't do me any good, all I'm doing is sitting around the house"*. The challenges of becoming increasingly sedentary was also heightened by older age, as Dan noted *"you can't do much else really at my age really, when you get to this sort of standard, you sit down and it's no good for your health, you need to be active, but you can't be active."*.

5.4.2.2 Emotional Wellbeing

The emotional impact associated with having a CRC was raised as a prominent daily challenge. Through facing daily physical challenges, participants felt they could not continue life as 'normal' in the same way as before they developed a CRC. Being unable to keep up with friends, family, maintaining their home and their hobbies made participants frustrated and upset as they felt the limitations were *"taking over"* (Joti) their life. This was particularly challenging for participants who recalled previously being able to complete certain activities and tasks without any difficulties. For example, Fred described needing to sit down and rest when out with his family, which was difficult for him as *"I love going out with my grandchildren and you can't keep up with them"*. Likewise, Nelly described that the physical limitation of being unable to maintain her home to her own standards was difficult for her emotionally. She

described finding it more challenging to accept the emotional difficulties as she felt *"depressed"* when the physical limitations *"builds up and gets you down"*.

5.4.2.3 Guilt and Stigma

Guilt and stigma associated with having COPD was experienced by participants. They believed they were stigmatised as COPD is related to cigarette smoking, leading to people describing their condition as a *"self-inflicted"* (Jin) illness. The perceptions of stigma were evident in the interviews, as participants who had never smoked wished to emphasise this to me (e.g. *"I've never smoked, that's the first question people ask"* (Irma)). Irma described feeling *"resentful"* towards smokers when she was first diagnosed, stating that she *"wanted to blame people, if I saw people in the street smoking, I wanted to go up to them and say 'hey! This is what you could do to yourself and this is what you are doing to other people'"*. She felt that the stigma towards her was unfair, as she lived *"through an age where mum and dad smoked, everybody around you smoked at work"* and effectively was a *"passive smoker"* through no choice of her own. Similarly, Mary believed that blame around COPD was not simply a perception, but is *"societal views ... the views that are out there"*. She discussed how people stigmatise the condition but *"they're not thinking about who you were at the time you started smoking ... impressionable"*. There were also references to participants blaming themselves for their condition, such as Tina, who found it difficult to quit smoking, and referenced how developing COPD was her *"own fault"* and how she believed that she *"should have known"* that her smoking would lead to a health condition.

There was also reported stigma experienced in relation to the particular symptoms of CRCs, particularly coughing. Participants discussed how they felt uncomfortable coughing in public as *"people don't like people coughing in general because they feel they are passing something on"* (Seb). In extreme circumstances, coughing led to *"wetting myself or soiling myself"* (Irma) which impacted how willing Irma was to leave her home and socialise. One way participants felt better about their symptoms was

when they were around other people with the condition, such as at support groups, as *"people can cough their heads off and no one complains"* (Ken) due to a shared understanding of life with a CRC.

5.4.3 Management Approaches

The following sections provide detail on the approaches and attitudes that participants described for managing their condition. The two key themes described below are (1) 'reactive management approach' and (2) 'knowing yourself'.

5.4.3.1 Reactive Management Approach

Some participants took a 'reactive' approach to self-management. This described an approach whereby participants did not feel it was necessary to self-manage or monitor their condition when they felt well, but instead would 'react' to feelings of symptoms or incidents. This was contrasted to other health conditions which participants had, such as diabetes, where participants felt there was a stronger need to monitor each day regardless of symptoms. For example, Ken discussed being *"more conscious"* of his diabetes and how diabetes management has *"all got to be done"* each day whether or not he feels symptoms as *"it hits me hard"*. Whereas he described the effect of not taking COPD medication as less immediate, so he may decide not to take his COPD medication if he feels minimal symptoms and thinks he can cope without it. For Tina, her *"diabetes is easier to monitor"* as *"you know that if you take your medications that it's going to be okay"* unlike with COPD. She found regardless of taking medication and doing *"everything you should"*, she could *"have a bad day"* with her COPD as it was more *"unpredictable"* which makes COPD less suitable for monitoring in the way that diabetes is. However, she discussed how, for a short period of time, she recorded daily peak flow readings at the suggestion of her HCP after experiencing a COPD hospital admission. During this time, she was motivated to track her breathing after her hospital admission *"so they [the HCPs] could see what was going on ... I*

thought if they could see a pattern that maybe I can't see, they could give me the solution, which is why I did it". Beyond this, she did not engage in self-monitoring her COPD symptoms and did not believe doing so each day would be valuable for her.

Some participants took a reactive approach to managing their condition even if this contradicted advice given by their HCPs; who may prescribe them medication to take regularly or instruct them to record certain readings. There was acknowledgement from participants that more consistent self-management and monitoring practices could alleviate the severity of the bad days, but it was not an approach that they actively took in practice. For example, Nelly acknowledged that consistent monitoring of peak flow readings could be beneficial for her COPD yet *"I've never done that because my symptoms aren't so bad that I've needed to"*, she continued to justify this by stating *"when I'm OK, I don't do anything, it's just when things go down I take action"*. Similarly, Dan discussed taking his prescribed oxygen when he felt that he needed to, in contrast to his HCP's instructions: *"if I need it [oxygen] I'll take it, if I don't then I don't bother with it, that's the way I deal with it"*. Likewise, Ken described how he prefers to take certain inhalers if he feels he needs to, rather than taking them consistently as a preventative measure:

> *"Sometimes I'll leave it ... because I think I don't need it *laughs*, it's silly really, but I think I'll be alright in a minute... I don't need it. But then 10 minutes later, I'm like, where's that spray! ... I'll try not to take it because I think it [the symptoms] will go away, but it won't, it doesn't... I try and hang on to see if it goes away"*.

Participants were asked if they kept diaries or metrics about their condition as part of the self-managing process, or if they would consider doing so in future. Some participants believed that their symptoms being under control meant that there was no need to record this information (Jin, Nelly, Maggie), but may consider this *"when I'm feeling not so good"* (Nelly) rather than *"when I'm feeling well"* (Nelly), as being well provides no *"necessity to monitor it, if I was worse that would be different"* (Maggie). However, Hedge emphasised the importance of a consistent approach to

self-management instead of waiting *"until you're actually poorly"* as *"you might be too poorly by the time you do something, you might have missed the chance"*, as deterioration can *"make your symptoms go worse permanently, you can lose some of your lung function"* (Mary).

5.4.3.2 'Knowing' Yourself

The notion of 'knowing yourself' was discovered with participants. This related to understanding symptoms and capabilities over time and eventually reaching a point where additional support is no longer required. Participants recalled the early stages of their condition, and how they felt that triggers were *"unpredictable"* (Jin) and how *"at first it was all a mystery and it was terrifying"* (Tina) as she was *"panicking all the time"* (Tina). Yet, over time, participants began to adjust with life with COPD and began to *"know myself"* (Irma), including what their limitations and capabilities were. Hedge recalled how he was *"so well aware"* of his condition now that he could *"forecast"* exacerbations. Whereas Tina, believed she could now *"read into it [her symptoms]"*, as she became *"much more aware now with everything that's going on with my chest"* as her experience living with the condition grew. For Joti, having lived with her asthma for so many years meant she was well aware of her triggers, and *"know[s] for a fact when I get a cold that's in, I'm in trouble for 3 or 4 weeks ... I already know that"*

The effect of 'knowing yourself' over time caused some participants to outgrow certain self-monitoring practices which they initially adopted to learn their capabilities. Both Dan and Irma commented on how they abandoned their activity trackers as *"you know how far you can go, you know when to stop"* (Dan) and how *"the walks I do are the same walks I did then, so I have an idea of how far I've been walking"* (Irma) so *"I feel like I've been managing without having to use that"* (Irma). Whereas Tina discussed how she did not use her peak flow meter as *"I know already my chest is bad, so I don't need that little red dial to tell me"* and the reading *"means very little to me"*. This demonstrates how technology enabled support helped participants to 'learn' about themselves, but over time they felt the value obtained from these tools

was outgrown.

5.4.4 Experience of Self-Monitoring Technologies

Participants who had experience using self-monitoring technology for their CRCs were asked about them. Amy, Dan, Hedge, and Seb had all used self-monitoring technologies for their CRC either currently or in the past. They had experience using the same diary-based smartphone app, called 'How Are You Today'[4]. The app was being promoted by different healthcare services in the region, which explains why the four participants had experience using it specifically. The app required them to record data about their symptoms daily for self-reflection, while also providing a set of recommendations for the day based on what the user reports (such as 'consider contacting a healthcare professional'). Each week the data would be shared with the user's HCP. Amy was an avid user of the app and had been using it for two years consistently before being interviewed. Hedge, Seb, and Dan were no longer using the app and their responses were reflective of their past experience in doing so.

Participants were asked how they engaged with the app throughout their time using it. Amy, Seb, and Hedge had all used their personal smartphones to engage with the app each day. Amy noted how her use of the app has become part of her *"routine"* just *"like getting up, going to the bathroom, cleaning, tea"*. However, she said being symptomatic serves as a strong reminder to record her entries *"because [being unwell] it reminds me, because I am wheezing a bit, I am a bit puffy, I better fill [the app] in"* whereas *"if it's too early [in the day] I can't tell how I am today, so I leave it [until later]"*. Dan did not have a smartphone or internet connection, so he used the app by phoning a relative each night who had downloaded the app and input the answers for him. Dan felt the approach he had to take was ineffective, as it relied on

[4]'How Are You Today?' Accessed February 6, 2020 from https://play.google.com/store/apps/details?id=com.intelesant.copd&hl=en_GB.

phone calls each day to have the information recorded. For Dan, smartphones *"cost too much"* and he preferred using his basic mobile phone to make phone calls, and his computer for any other tasks.

5.4.4.1 Linking App Data to Support Networks

The importance of self-monitoring data being linked to specific support networks was raised in the interviews. Having somebody 'check in' with participants and their data was seen as positive and motivating for participants to continue using an app for self-monitoring. Amy used a feature within the How Are You Today app to share her data with her daughter, which she believed was positive for her overall management as her daughter could oversee her entries and raise any concerns with her. Seb was using a new diary app each day[5] which functioned similarly to the How Are You Today app, but where data was reviewed every day by respiratory nurses which he felt was *"proactive"* as *"whenever I'm putting something on there, someone's reading and taking notice"*, which motivated him to record each day as *"if there's anything wrong, they ring me"*. Hedge strongly believed that self-monitoring data that is sent to HCPs or carers, who should act on potentially concerning entries, *"would be the epitome of success"*. He expanded further by describing a system *"that would just flag up or even send a signal to, it may be a GP or respiratory clinic, that Mrs X's sats [oxygen saturation levels] and observations are poor, it might be a good idea to pay her a call"* or that *"sent a text to your partner or to whoever you've designated as your carer"*.

[5]This was not an app available on the market, but was part of a clinical trial looking at predicting exacerbations based on self-monitored data.

5.4.4.2 Keeping Up with Evolving Needs

When discussing reasons for discontinuing the use of the How Are You Today app, participants mentioned that the app did not keep up with the evolving needs of their condition. Participants commented that the app was unable to provide them with new knowledge about their condition, which was seen as important for it to retain value. Participants raised the point that self-monitoring technology should provide value to the user beyond simply generating data, and something more than what can be achieved with just a *"piece of paper"* (Hedge). Rather, it was discussed that the tool should provide actionable data back to the user that can be used to inform and adjust self-management practices, such as predicting exacerbations. Hedge felt that he was at a stage in his condition where he knew himself when it was time to seek medical help. Therefore, he felt the recommendations from the app were not valuable when he was being told to seek professional help: *"I don't need an app to tell me that [I should go and see my doctor]"*. Similarly, Seb felt that the questions asked by the diary app were out of sync with his current condition stage, noting: *"I have emphysema so I'm going to be breathless [commenting on the alerts raised when he input that he was breathless]"*. Seb eventually abandoned the app when it was clear that it could not learn that being breathless was normal for him and not the basis of which to seek help. He felt that the app would be useful for somebody adjusting to life with a CRC, but he was *"too far on this journey for this app to be of any use"* and *"that it would be better for somebody in the early stages"*. This demonstrates how participants have different needs according to their condition stage and length of time having had their condition.

5.4.5 Summary of Interview Findings

Overall, there were five key findings from the interviews:

1. Participants lacked information about CRCs, both at diagnosis and more long-term.

2. Participants have experienced stigmatisation due to their condition and its symptoms.
3. Some participants adopted a reactive approach to self-managing their CRC.
4. Those at different stages of their condition will find value in different types of self-management tools, but overall tools must be simple and accessible.
5. Self-monitoring technology that links with a person's support network is seen as valuable, and these support networks should ideally respond to concerns outlined by the data entries.

5.5 Workshop Findings

The workshop with 11 participants (split into two main groups: Group 1 and Group 2) aimed to build on some of the themes about information needs and support avenues that were discovered in the interviews. The following sections report on the findings from the workshop discussions and are split by activity. The first workshop activity centred on defining information needs, by exploring the self-management advice that participants would give to a hypothetical friend who was newly diagnosed with a CRC. The second activity focused on discussions about accessing support, comprising of discussions around how participants seek support and the respective barriers involved in doing so.

5.5.1 Feedback on Information Needs

The following three sections present the main findings from the information needs activity, in which participants were tasked with exploring self-management advice which they would give to a hypothetical friend that was newly diagnosed with a CRC. If an excerpt is attributed to a particular group, this indicates that the text has either been taken from the respective group's collective pamphlet (i.e. not deriving from a

single participant, but their joint agreed pieces of advice) or an individual pamphlet from one of the group members (these were not labeled with participants' names). A total of nine themes were identified from the thematic analysis for this activity. Some themes were not included in the presentation of the findings due to their similarity with the interview findings, such as 'lack of information at diagnosis' or lack of prominence in discussion, such as 'the need for accessible language' (describing how participants required more accessible language to be used when having their condition described to them). The remaining themes were then condensed into three key themes around (1) 'lack of knowledge from healthcare professionals'; (2) 'diagnostic uncertainty'; and (3) 'learning to understand your illness'.

5.5.1.1 Lack of Knowledge from Healthcare Professionals

Participants believed that an important part of managing their CRC was having meaningful interactions with their HCPs, through which they could learn useful information about their condition that could help them to improve their self-management. However, participants discussed their disappointment with the perceived lack of knowledge that general practice staff had about CRCs (particularly COPD). Participants felt that this lack of knowledge was the reason they did not obtain adequate information at diagnosis or have meaningful interactions with general practice staff. One of the prominent pieces of advice that was drawn out from the information needs activity was around telling newly diagnosed people to ask general practice staff *'would an early referral to a COPD specialist be useful?'* (Group 2). When discussing this advice in more detail, participants mentioned *"we want a specialist in the surgery that knows the ins and outs of COPD"* (Tony), which would *"give us a clearer picture of what we are up against"* (George) and *"how to handle it"* (Lisa), which means *"they can explain exactly what you have, what the prognosis is, what medication you'll need ... so that they who have the in-depth knowledge could actually answer all your questions"* (Rose). It was raised that there is a need to *"explain exactly what the tests mean ... they don't really explain what or why they're doing these things"* (Elliot) which is important for understanding the condition and effectively self-managing. One partici-

pant, George, even advised that *"if you can't get into your doctors, you can go to the accident and emergency walk-in centre, and they're better than the doctors"* as a way to receive appropriate treatment and support for the condition, along with getting in touch with *"respiratory nurses which just deal with respiratory problems"* (May). The group further reflected on their unsatisfactory experiences with general practice staff, noting that they have been *"shown the wrong way"* (George) to use their inhalers, which they had only been corrected when specialist nurses visited the support group to demonstrate how to use inhalers. Likewise, Daisy (aged 43) mentioned that her COPD symptoms were dismissed too easily by her GP as she was repeatedly told *"people your age don't get it"*, while Tony stated that *"sometimes the information they [GPs] give is contradictory"*. As such, these experiences prompted participants to advise a newly diagnosed person to ask for a referral to a specialist to ensure they would receive meaningful advice and appropriate support.

5.5.1.2 Diagnostic Uncertainty

Another prominent theme discovered in the workshop discussions was diagnostic uncertainty; participants discussed the medical uncertainty around CRCs which resulted in uncertain diagnoses. Participants discussed their experience of their diagnosis being formally changed by HCPs over time, and sometimes reverting back to a prior diagnosis. One participant had included the uncertainty around diagnosis as a node of caution to a newly diagnosed person: *'my wife was told she had asthma, and then she was told she had COPD, later she was told she didn't have COPD but had asthma. Conclusion: we need more accurate diagnosis'* (George). This uncertainty was a common experience across the group, as participants recalled how *"they couldn't make their mind up if I had COPD or asthma, or both"* (Lisa) and *"they still can't figure out if I've got asthma or COPD or not 10 years on. I've got bronchiectasis, I'm diagnosed with that now ... it's a different thing all together"* (Elliot).

Some people perceived their diagnosis to be made without careful consideration: *"if you say you've been a smoker they tend to say you've got COPD without*

really thinking about it" (George). Moreover, there was confusion around exactly what COPD was, with some participants believing it was *"another term"* (May) for emphysema, or a new name for *"what they used to call bronchitis"* (Lisa), rather than COPD describing a set of CRCs. The challenge of being unsure about their condition meant participants felt confused about how to manage their condition appropriately, the likely cause and triggers of the condition, how to adjust to it, and felt unsure for their future due to the uncertainty. For this reason, participants emphasised that newly diagnosed people should *'be assertive'* (Group 1) with HCPs, and be sure to *'ask questions'* (Group 1) to seek further clarity on their diagnosis.

5.5.1.3 Learning to Understand Your Illness

An important piece of advice that participants highlighted was around taking the time to *'learn to understand your illness'* (Group 2), by learning how it effects each person individually both physically and emotionally. This was not seen as explicit knowledge, but a process of *'trial and error'* (Group 1) arising from embodied experience, with every case being *"really individual"* (Tony). However, participants agreed there were still valuable opportunities to advise a newly diagnosed person on how to begin navigating the discovery process. One of the most important first steps in learning to live with the condition was to not *'blame yourself'* (Group 1) or not to *"allow yourself to be told it's your fault"* (George), as *"blaming yourself does lead to other problems"* (George) such as mental health conditions, and a reluctance to seek help or help oneself. The concern about blaming oneself stemmed from the stigma around CRCs, such as COPD, developing primarily through cigarette smoking (but also environmental factors such as certain industrial occupations). Daisy reflected on how she would comfort her mother, who also had COPD, by reinforcing that *"you haven't done this"* as a result of being a smoker. Participants believed that this was an important emotional 'hurdle' to overcome when being diagnosed and preparing to adjust to life with a CRC. They argued that people could become better emotionally equipped to deal with the condition once addressing any notions of self-blame.

Learning about physical triggers and symptoms was another area which participants raised as important for self-management. Group 1 noted that newly diagnosed people should be told *'it can't be cured, but a lot can be done to slow the process'* (Group 1) and *'there is so much you can do for yourself'* (Group 1) and that this can help enforce a positive mindset for self-managing the progressive condition. Although making sure people *'get the right medication'* (Group 2) that works for them was very important, participants noted that *'a pill is not always the answer'* (Group 1) and there are additional ways in which people can enhance their quality of life through personal self-care practices. Some participants discussed specific self-care practices that could be helpful for learning about how their condition impacts them, including avoiding environments such as *"a smoky atmosphere, or if it's really damp, or very cold"* (Rose), finding ways to exercise such as *'walking on flat ground if hills are beyond you ... any exercise is better than none'* (Group 1), ensuring proper breathing as *"a lot of people with COPD do not know how to breathe correctly ... I mean my lungs are seriously shot to pieces ... but I've learnt to breathe."* (Tony), and *'mindfulness courses'* (Group 1) to help deal with breathlessness and anxiety. It was stressed that this advice can help newly diagnosed people to experiment with different techniques that can help them to self-manage their condition, but also ensure they *'don't give in to it'* (Group 1) and can *'meet the challenges'* (Group 1) while trying to *'carry on as normal'* (Group 1).

5.5.2 Exploring and Accessing Support

The following three sections describe the findings from the discussions around seeking support. There were a total of five themes arising from the thematic analysis, which I condensed into three key themes that explored different support avenues. During this activity, participants made reference to discussions had during the previous activity around 'lack of knowledge from healthcare professionals' and 'diagnostic uncertainty', which I did not include in the findings for this section to avoid repetition. The three key themes described below are (1) 'being selective with support'; (2) 'discovering

support groups'; and (3) 'attending support groups'.

5.5.2.1 Being Selective with Support Networks

Participants discussed the ways in which they were selective about who they approached for support when they felt unwell, as they did not want to cause worry or concern to certain people. Participants described how their evident shortness of breath when feeling unwell can make their family members *"worry about your breathing"* (Elliot), which made participants reluctant to share how they felt as they did not want cause distress to their family. Some participants discussed how this reluctance created a barrier to support, as *"sometimes you think, I wish I could tell them blah blah blah, but I don't want them to know just how bad I am today"* (Daisy) and this leads to feelings that *"you have to"* (Max) deal with it alone as *"if I tell them about it, is that going to affect them [mentally] as well?"* (Daisy). To overcome this, other participants discussed sharing their concerns with support group members who understand the condition: *"sometimes when I'm not well, and I'm breathless, I'd rather ring somebody in Breathe Easy [the group] to tell them I'm not well, rather than family, so I don't worry them, you know what I mean?"* (Lisa). In fact, participants described how they would telephone one another outside of group meetings or *"go 'round and see how they are"* (Lisa). Being part of the support group, *"a community that understands your problems"* (Tony), was seen as valuable for providing emotional and mental support without the concerns of 'burdening' or worrying family about the reality of how they feel during their 'bad' days.

5.5.2.2 Discovering Support Groups

Participants emphasised that support groups were *"tremendously"* (Rose) conducive to feeling part of a community, where people could receive support and advice on an ongoing basis as *"unless you come to something like this where you've got people who have gone through it, or who are going through it, you wouldn't know, I wouldn't*

have known anything, I'd have been no nearer [in terms of support and advice]" (Rose). However, participants believed that learning about the existence of support groups was a challenge among people with CRCs. Many participants found out about the group through researching online or seeing it *"advertised on the wall in the notice-board at the doctor's surgery"* (Linda), with one participant being referred by their GP practice (Lisa). However, participants believed that HCPs should be actively informing people with CRCs about the groups, and not leaving them to discover the groups themselves as *"there are thousands of people suffering from COPD or breathlessness"* and *"they haven't got enough information"* (Max) about the existence of support groups. Some participants described trying to campaign for better awareness about the groups through bringing material by the British Lung Foundation into healthcare centres, but noted *"it's very difficult to get notices put because so many people want to put notices up"* (Linda) and how the GP practices refused to let them leave material as they *"would not allow it ... they just didn't want them"* (Tony). This frustrated participants as they noted that *"it's the fourth biggest killer [COPD], but it doesn't get the recognition"* (Daisy) and that leaving material at healthcare services was believed to be the most effective way of advertising the support groups and awareness to people with, or at risk of, CRCs.

5.5.2.3 Attending Support Groups

In addition to the challenge of learning about the support groups, participants discussed that there were challenges related to physically attending them as *"there's lots of people that would come [to the groups] but they can't get here, transport is a real problem"* (George). Being able to arrange travel to the groups was highlighted as extremely difficult for people, particularly as CRCs contribute to limited mobility and fatigue. Participants talked about how they travelled to the groups, often being driven by family, friends, or carpooling together. They talked about how some people do not have this mobility support and *"can't be going out"* (Max) alone and may have anxiety over *"what happens if they get serious"* (Max) while travelling alone. It was also suggested that some people may struggle to make *"the effort to come"* (Max) due

to challenges with mental health and wellbeing associated with CRCs. Participants described how sometimes existing members *"can't always get here with health issues"* (Tony) and that they used a closed Facebook group to discuss each meeting and share information, so that existing members that can *"read whats gone on and not feel out of place [by not having attended the meeting]"* (Tony).

5.5.3 Summary of Workshop Findings

Overall, there were five key findings from the workshops:

1. Participants felt HCPs lacked information about CRCs, which was a barrier to the support they could provide.
2. Learning and developing an understanding of the condition is an individual process that can be made easier through sharing pointers and experiences across the CRC community.
3. Some participants were selective with the type of support they used when sharing experiences of poor health as to not worry or 'burden' family.
4. There is difficulty in discovering support channels as there are limited opportunities to advertise them.
5. Physical support groups can be difficult to access for people with CRCs due to transport issues and challenges associated with leaving the home.

5.6 Discussion

The following sections synthesise the findings from the survey with 147 respondents (to gather a broad understanding of the CRC community's self-care experiences, everyday device usage, and uses of technology for self-care), interviews with 13 participants (understanding the rich lived experiences of having a CRC), and workshop with 11

participants (exploring information needs and support avenues). The discussion is centred around design considerations for CRC self-management and self-monitoring technologies. The three discussion points focus on (1) 'designing for reactive management approaches'; (2) 'knowledge acquisition and evolving needs'; and (3) 'designing for inclusivity and reach'.

5.6.1 Designing for Reactive Management Approaches

The interviews revealed that some participants took a reactive approach to managing their own care. Participants felt a heightened need to self-monitor and take medication when they felt unwell, compared to a consistent approach that, in some cases, was advised by HCPs. Some participants discussed that they believed this reactive approach would extend to their potential use of self-monitoring technologies. Likewise, survey findings demonstrated that many respondents did not track symptoms using a diary for self-reflection or sharing in clinic[6]. This highlights how current models of self-tracking, which stress the importance of long-term consistent data points generated by the user (Pols, 2012; West et al., 2018), may not align with the symptom transience and gradual fluctuations that can occur with CRCs. The concept of designing for symptom transience has been explored in HCI research around Parkinson's disease (McNaney et al., 2015; Mishra et al., 2019; Nunes and Fitzpatrick, 2015, 2018) and migraines (Schroeder et al., 2018), highlighting the need for self-monitoring and tracking tools to support variability in condition state. Particularly, Nunes and Fitzpatrick (2015), discussed how people with Parkinson's will adjust their self-management practices to deal with periods of stronger symptoms, contrasting with conditions such as diabetes that require more stable and consistent self-management. This resonates with the reactive patterns of management that was evident with the interview participants, who in some cases, also contrasted this

[6]This is not to say people would not be willing to do this, just that they routinely did not.

approach to how they managed their diabetes. There is a need for self-monitoring technologies to adapt to reactive styles of management. This changes the way we think about the practice of self-monitoring for CRCs, shifting from a stable process of self-monitoring rhythmically, to a flexible process that can support more intermittent habits of monitoring.

Reactive management approaches are not unusual, as consistent self-observation of one's condition can be detrimental to their mental wellbeing (Ancker et al., 2015; Craven et al., 2013; Lupton, 2013; Nunes et al., 2015; Oudshoorn, 2011; Pols, 2014; Yun et al., 2010). Particularly, Lupton (2013) discussed that the emphasis placed on self-monitoring and self-surveillance of a person's chronic condition can be overwhelming and depressing. For respiratory care specifically, Craven et al. (2013) found that daily self-monitoring of asthma symptoms (specifically coughing) on an app were intrusive for a user, making them more conscious of their symptoms, resulting in more coughing. Similarly, COPD patients in a study by Pols (2014) felt that lung function readings were counterproductive as they could only be interpreted in unhelpful ways, which did not improve the situation for the patient. Although tracking this information may lack value for the patient, Pols (2010, 2014) described how physiological readings can depict a condition of one's body in a way that may not be experienced directly by the patient themselves. Thus, there may be instances where it would be clinically meaningful to track certain symptoms even if this does not align with what a patient deems meaningful. However, too much emphasis on the generation of clinically useful data at the expense of the experience of living with the CRC can reinforce Parsonian notions that the patient is not autonomous and must 'comply' with the demands of the HCP in order to treat their sickness (Parsons, 1975; Storni, 2010).

Identifying this reactive management approach demonstrates how consistent long-term tracking practices from the individual can interfere with how some individuals organically routinise, organise, and manage their everyday life to accommodate living with a CRC (Lupton, 2014c). More passive approaches to monitoring could be a more promising approach for people that adopt a reactive style of management. For example, using audio sensors to detect wheezing (Chatterjee et al., 2019) or the use

of smart inhalers (such as reliever inhalers) and peak flow meters which record usage and detect increased use (Chen et al., 2020; Perez, 2015). Heightened use of tools and objects that are designed to help with self-management could be an indication of a struggle or a decline in health, which could prompt user engagement to monitor when necessary. For example, the survey data showed that medication and pulse oximeters were most commonly used by the community to self-manage. Therefore, increased contact with them could suggest a change in health condition, which could be used to generate data points without overburdening people for day to day additional data input.

I do not argue that technologies that require more explicit user input lack value for people with CRCs. Instead, I argue there may be specific periods or stages of the condition where explicit user input is more acceptable and more valuable to people with CRCs. For example, Anastasiou et al. (2018) built an asthma exacerbation prediction system aimed at predicting severe exacerbations of patients from their homes. Through capturing daily peak flow readings, an asthma questionnaire response, and medication use, the system was able to predict asthma exacerbations seven days in advance. This may suit periods when individuals with CRCs are unwell over a long period of time, such as those who are in the acute stages of their condition or are recovering from a recent hospitalisation. Outside of these scenarios, some individuals may feel that they 'know themselves' and their symptoms well enough that they do not require day to day support. This does not suggest that these technologies have no place or value in CRC self-management, or that these reactive approaches apply to all individuals with CRCs. Rather, I wish to emphasise that it would be useful to consider how self-monitoring practices may be a temporary practice that some people choose to take in certain situations and circumstances. This is in contrast to viewing the process of self-monitoring as something that begins and ends indefinitely, without consideration of the condition stages and experiences that individuals with CRCs are living with.

5.6.2 Knowledge Acquisition and Evolving Needs

The concept of outgrowing certain self-care practices was explored, as interview participants eventually learnt more about their condition and capabilities as time progressed. This relates to the chronic illness trajectory (Corbin and Strauss, 1991), whereby individuals experience different phases of their illness as their condition progresses (Mccorkle and Pasacreta, 2001). During the interviews, participants raised the concept of 'knowing yourself', in which they abandoned activity tracking devices that supported knowledge building around their capabilities once this knowledge had formed. This was also evident with interview participants that had lived with the condition for many years, who expressed that their development of experiential knowledge about their condition warranted new needs (such as no longer learning about their condition but forecasting potential exacerbations). For instance, we saw how one interview participant felt the value provided by a symptom monitoring app did not align with the advanced stage of his condition. The concept of abandoning technology after reaching certain goals has been explored in previous self-tracking work (Epstein et al., 2015).

More specific to concerns around designing for different life stages, Kelley et al. (2017) discussed the ways that self-monitoring tools for mental wellbeing in young adults should be designed for their different life stages. Similarly, Pollack et al. (2016) explored how technology should support hospitalised patients to self-manage gradually as to not overwhelm them with information before discharge, while also accounting for how their needs change and vary over time. As CRCs are progressive conditions, there is a need to design tools that consider the different stages of the condition but also the length of time having lived with the condition (which are two different axes on the illness spectrum). If self-monitoring technologies are flexible enough to follow the progression and experiences of the person with a CRC, it could offer more value to the individual. As CRCs progress over time, the experience of living with the condition also matures, thus progression of the *condition* and progression of the *experience* changes an individual's needs over time. However, progression of the

condition and progression of the experience do not necessarily advance at the same pace.

Participants from both the interviews and the workshop lacked enough information about what their condition was, what it meant for their life (also evident in the survey data, section 5.3.3.2, pg. 167), and how to self-manage when being diagnosed. They lacked what Pols (2012) described as 'clinical knowledge' (knowledge accumulating from multiple sources including scientific literature, test results, and patient reports) and 'practical knowledge' (knowledge of living and dealing with the condition through embodied experience[7]). They felt that both types of knowledge were important for understanding and self-managing their condition; and expected clinical knowledge to help facilitate the development of practical knowledge. However, the lack of information about CRCs provided at diagnosis and the lack of knowledge of general practice staff, combined with uncertain (and changing) diagnoses, interfered with their self-management journey and how they made sense of their condition. Medical literature has also reported on the ambiguity in diagnosing COPD due to changes in the agreed thresholds for spirometry results (Pellegrino et al., 2008), similar characteristics to other lung conditions (Soler-Cataluna et al., 2012), having more than one CRC at the same time (Barrecheguren et al., 2020), and lack of training in delivering spirometry tests and interpreting results (Bolton et al., 2005). To deal with the dissatisfactory encounters with general practice staff, workshop participants talked about the value of being referred to respiratory specialists, who provided a route to better clinical and practical knowledge about their condition.

Some forms of practical knowledge arise through the learning process of living with a condition (Pols, 2012). Knowledge that develops through embodied experience can be somewhat incommunicable (Williams and Ryan, 2017). However, workshop participants emphasised how some tips and advice are transferable and valuable for

[7]Note that HCPs can still contribute practical knowledge to the patient by providing self-management advice based on the patient's reported problems.

starting and carrying out the journey of living with a CRC. Pols (2012) talked about 'know-*how* knowledge' (knowing how to do something embedded through techniques and methods) and 'know-*now* knowledge' (knowing and interpreting what to do in a new, unseen situation). The workshop participants discussed being able to share experiences of both know-how and know-now knowledge during meet ups, which greatly improved the inventory of knowledge that participants had about living with their condition. For instance, being aware that certain environments can exacerbate the condition (to inform know-now knowledge) or breathing techniques they had learnt that helped with breathlessness (to inform know-how knowledge).

Clinical and practical knowledge are clearly important components for being able to best manage and navigate life with a CRC. Though interview and workshop participants felt this knowledge was generally lacking, its existence within defined groups was acknowledged (specialist respiratory HCPs, experienced support group members, etc). The challenge was in *accessing* these defined groups where the knowledge exists, with participants noting that a change in attitude can help them to obtain this knowledge (by being assertive with HCPs about information needs and actively asking questions) or by physically locating this knowledge themselves (through searching the internet and physically attending support groups). In some cases, there can be challenges in *discovering* this knowledge in the first place (discovering information about specialist respiratory HCPs and support groups). Further physical barriers to accessing knowledge occur when considering the significant mobility and fatigue challenges faced by many participants (evident across the survey, interview, and workshop data). This can impact how far individuals can physically go to obtain needed knowledge (such as attending healthcare centres and classes, and support groups).

These challenges present an opportunity for digital solutions to aid in providing sources of information on starting and maintaining the self-care journey. Previous work has looked at the ways in which technology can provide digital support for people with CRCs. For example, Pols (2012) described how COPD patients collaboratively developed and shared practical knowledge through webcam meetings to overcome

limitations imposed by mobility difficulties. This demonstrates the value that technology can provide in remotely bringing together communities for information sharing and strengthening self-efficacy. More specific to online information provision, positive stories and information sharing have been shown to enhance and strengthen knowledge of asthma, expanding on the 'basic' information provided by healthcare professionals (Sillence et al., 2013). McNaney et al. (2018) engaged the Parkinson's community in the co-creation of health information resources, allowing information needs to be designed by the community themselves. This resulted in the creation of a radio channel which involved clinical and personal perspectives about the condition. Collaborating with respiratory support groups to co-create their own information resources could be a beneficial way to build practical knowledge. It could also help to build a widespread sense of community which traditionally exists in physical support groups.

Through providing an online platform for people with CRCs to co-produce and share practical knowledge (such as know-how and know-now knowledge), advice on gaining more meaningful support from healthcare services (such as being assertive, asking questions, suggesting referrals), pointers to additional avenues for support (such as physical support groups), and feedback and recommendations on self-management technology (which reportedly occurs in support groups), people of different physical abilities can be better supported in acquiring important information and knowledge that they need to (self-)manage their condition. This also supports information provision and helps build confidence in people that face mental health challenges associated with CRCs who may find it challenging to seek this support. Considering many survey respondents used the internet to browse for information (88% of all respondents), and some used the health related websites and forums, online information provision can be seen as an accessible and useful way to support the CRC community.

5.6.3 Designing for Inclusivity and Reach

The following sections below discuss 'reaching out for support' and 'accessible solutions over novelty solutions' in relation to designing for reach across the CRC community.

5.6.3.1 Reaching Out for Support

Facing stigma in association with a CRC has been reported in previous work, particularly relating to smoking and wider societal blame (Berger et al., 2011; Halding et al., 2011; Johnson et al., 2007a), feelings of embarrassment about symptoms such as coughing, breathlessness, and increased sputum (Berger et al., 2011; Snadden and Brown, 1991), and not wanting to 'burden' others with the condition (Berger et al., 2011; Earnest, 2002). This stigma can negatively impact people's illness experience, cause feelings of defensiveness, and contribute to disengaging with healthcare services (Berger et al., 2011). I found that participants experienced stigma in their everyday lives about their CRC, this was experienced from HCPs (who were perceived as being dismissive with participants if they admitted being current or former smokers), society more widely (who perceived the condition to be self-inflicted), and even self-blame in some cases (believing COPD was a form of punishment for smoking). Experiencing stigma created barriers for some participants to accept and adjust to life with the condition, creating difficulties in fostering a positive outlook for self-management. Examining how design can accommodate stigmatised conditions has featured in previous HCI work, for example around Type 1 diabetes (on how to design more discreet medical devices) (McCarthy et al., 2017) and HIV (designing for (non)disclosure on sex-social apps) (Warner et al., 2019). However, the stigma I have found in context to CRCs reportedly affected how participants' felt they could seek support for their condition (opposed to how they engaged with specific technology and devices). In addition to stigma, workshop participants expressed wanting to avoid 'burdening' family members about their condition, leading to them being hesitant to reach out to family for support (section 5.5.2.1, pg. 187). This is important to note as

a lack of social support can have a negative effect on chronic illness self-management behaviours (Gallant, 2003), and the reluctance to seek help. Stigmatisation could also potentially impact how individuals with CRCs practice self-care.

Interview participants discussed that technology that linked their personal health data to peer support networks (such as HCPs, family members, and carers) was a motivation to track their symptoms and would be a valuable safety net for collaboratively discovering periods of difficulty. The importance of understanding self-care as a collaborative activity between people and their carers has been raised by Corbin and Strauss (1984) and more recently by Nunes and Fitzpatrick (2015) in the context of using technology for self-care of chronic illness. However, the feelings of guilt around 'burdening' family members could influence how people may report data about their symptoms, in a similar way noted by Dahl et al. (2018), who reported that COPD patients under-reported their symptoms when engaging telemonitoring technology to avoid 'burdening' HCPs. This raises the importance around how self-monitoring technologies that provide links to support networks are designed and how support networks are appropriately chosen. Previous work on COPD monitoring technology has incorporated features that allow data to be uploaded onto Facebook (Pereira et al., 2016). However, although the survey data showed people with CRCs used technology for social networking (60% of all respondents), data relating to CRC health is highly personal and people are selective with whom they wish to share this type of data. Therefore, there needs a stronger consideration about what channels people with CRCs would wish to share their health data with. Going forward, the ways in which personal health data is represented to different people in the patient's support network should be considered. For example, differing levels of information granularity for data sent to HCPs, family, and friends. For example, people with CRCs may wish to alert HCPs to small changes in their health but may feel that they are burdening or worrying friends and family by indicating this small change. It is important to be mindful of the way that personal health data is communicated to different people, and providing people with CRCs the option to customise this could be a positive step in encouraging and supporting people to share this data with their support networks.

5.6.3.2 Accessible Solutions over Novelty Solutions

In the context of empowering[8] patients through the use of technology, Skinstad and Farshchian (2016) have argued that some researchers may be more focused on achieving concept novelty than promoting empowerment in their development of technical solutions for health. Pols (2014) stressed the redundancy of handing patients technology that they cannot find ways to conveniently fit into their lives. Moreover, asking users to engage with a device which is not part of their existing lives and routines can be burdensome (Pols and Moser, 2009). The survey results showed that all respondents owned some digital technology, and that computers and laptops were the most commonly used device across all respondent age groups, with newer technology such as smartwatches being less commonly owned overall (but most likely owned by younger respondents). However, it is important to acknowledge that the use of technology in everyday life is not necessarily indicative of willingness to use and acquire technology to manage health conditions. Evidence suggests that respiratory conditions such as COPD are linked to social deprivation (Burney et al., 2014; Fullerton et al., 2011; Naess et al., 2007; Torres-Duque, 2017; Townend et al., 2017), as such it is important to note that those within the CRC community may not have access to costly technology for support.

It may be tempting to argue that as generations grow more technology proficient, older adults will engage more with a wider range of technologies. However, research by Knowles and Hanson (2018a,b) has shown that older adults may 'always' have a conscious rejection of newer technology due to their unique values inherent to their generational cohort (e.g. valuing face-to-face interaction over digitisation of services (Knowles and Hanson, 2018a)). This serves as a node of caution about assumptions that future generations will be more willing to engage with newer tech-

[8] Patient empowerment has been defined as 'a mechanism to facilitate self-led behaviour change' (Anderson and Funnell, 2010).

nologies. As generational values will change over time, the increasing digitisation of healthcare services and support may become a notable tension in future years. Particularly for people with chronic health conditions, where access to healthcare support would be required more frequently.

This introduces two important lessons for designing technology for people with CRCs: the first is ensuring that the design of digital solutions are community inclusive, the second is ensuring that solutions align with the values of the community. For example, Pereira et al. (2016) suggested that expanding their COPD exercise app onto newer devices, such as smartwatches, can increase users. However, expanding technology concepts onto newer technologies can exclude a large and older proportion of the CRC community. This is not to say that those with CRCs will not own newer devices, but raises the importance of considering the community inclusivity of the platforms that we design. Moreover, this approach of designing onto newer technologies to increase users is usage-focused compared to value-focused (i.e. first and foremost focusing on increasing user base rather than increasing value to users). In contrast to this, Yun and Arriaga (2013) demonstrate inclusive design when they created an education tool for children with asthma, which looked at improving asthma health outcomes through daily short message service (SMS) messages. They noted that using SMS messages, used heavily among pediatric patients at the time of the study, improved the response rate over the course of the study. Moreover, this decision was conscious: the fact that SMS messages were easy to use and something which pediatric patients engaged with in their daily lives motivated their decision for using them for the study. This demonstrates how favouring inclusive and considerate approaches to design, over the creation of 'novel'[9] concepts on newer technologies, can better support members of the CRC community.

[9] I am not arguing against novelty, rather, I am against putting novelty over patients' actual needs.

5.7 Study Limitations and Reflections

The most significant limitation to raise about this study is about self-selection bias and generalisability. I could only conduct research with participants who were willing to participate, which means my findings reflect a sample of participants who were willing to share their experiences and stories for research. I also actively used non-probabilistic sampling[10] to try to recruit interview participants who had used technology to self-manage their CRC, and then arranged a workshop with an existing support group to understand support channels and information sharing. This has implications for the generalisability of my results, as my findings cannot be said to reflect the entire CRC community.

Further to this, interview and workshop participants were mainly older adults, living in North West England, and were mostly white. Older adults are the demographic most likely to be diagnosed with a CRC like COPD, but there are people living with CRCs who are not older adults (Raherison and Girodet, 2009). Likewise, how people adapt to, and live with, any health condition will be influenced by their cultures, beliefs, and environment. I have not captured this diversity in this study, though I note its important for building a rich understanding of the lived experiences of CRCs (and the potential role of technology for support). This ultimately places limitations on the degrees of generalisability of this research.

Another important limitation is the lack of carers' perspective. Nunes and Fitzpatrick (2018) highlighted that, in some ways, carers can be thought as living with the chronic condition by being able to observe its effects in the person they are caring for. However, data was captured from only one carer in this study. Some workshop participants had CRCs while also caring for others with CRCs. One benefit of focusing

[10] In qualitative research, non-probabilistic sampling relates to identifying and recruiting people within your sample population that have the characteristics relevant to the phenomena you wish to study (Mays and Pope, 1995).

research on people living with the condition is that this approach can ensure research outcomes can provide greater benefit for the people with the condition (Nunes et al., 2015). However, this leaves a gap in my research, and creates an opportunity for future work in this area to incorporate the perspectives of carers.

I kept participants informed about this research while it was ongoing and after it had concluded. This was very important to me, because I had personal discussions with participants about important and sensitive topics about their life. I wanted to actively show them how their contribution to my research was being used. Whenever I was presenting a talk or writing a research paper, I would let them know. I consider this to be good practice in human subjects research, but it really struck me just how important it was after one of my last visits to a support group. One member wrote to me and thanked me for my continued updates and visits, noting: *'over the 16 years that I've led the group, a number of people have sought information from our members to support various projects and studies, but sadly most of them thank everyone on the days of their visits, then we never hear from them again'*[11]. Of course, a researcher's involvement on a project will always end in some way. However, I believe showing participants the value of their contributions is more than just 'good practice' and instead an important step in the research process.

Researchers in HCI are becoming increasingly aware of the ethical and practical challenges associated with research with communities, specifically what happens to relationships and technology when a research project finishes (Race et al., 2020; Taylor et al., 2013). This can be particularly difficult in healthcare HCI research, where they may be nothing tangible to show or give (in terms of technology) to participants at the end of the study. Therefore, keeping participants informed about the outcome of the research is an important way to demonstrate to them how their contributions are being used. Keeping participants informed could also help to encourage communities to participate in future research which could ultimately benefit them.

[11] Quote included with full consent.

5.8 Chapter Summary

This chapter has documented the rich lived experiences of CRCs and explored how technology could support this experience. Through carrying out a series of research engagements with the CRC community, I uncovered the challenges and opportunities involved when designing technology to support this lived experience. There was a total of 171 participants in this study. First, I conducted a survey with 147 respondents from the CRC community to understand: the everyday challenges they faced with their condition; how they used technology in their day to day lives; and their experiences of using technology to self-manage their condition. Next, I conducted 13 one-to-one interviews to build a richer understanding of the everyday challenges associated with living with a CRC, how people self-managed their condition, and their in-depth experiences of using technology to do so. Finally, I conducted a workshop with 11 participants to understand their information needs about their condition and explored different support avenues that were important to them.

The findings provided rich insights about the lived experiences and needs that people with CRCs have, followed by what this means for designing technology to support them. This includes: the reactive management approaches that some participants take to self-manage their condition (which is rooted in their perception of their condition and their individual needs); the need for technology to better support knowledge acquisition and the evolving needs of the condition (both in terms of clinical and practical knowledge about the condition); and the need to design technologies that are inclusive and accessible to the CRC community (particularly those who struggle physically and emotionally to seek support).

The next chapter builds on the previous two research chapters. It uses a case study approach to explore the lived experiences of self-monitoring COPD symptoms and sharing this data with HCPs. It explores the perspectives of both COPD patients and HCPs. It completes the perspectives explored in the previous two research chapters, by uniting HCPs and people with COPD to understand the opportunities for data supported decision-making through self-monitoring.

Chapter 6

Exploring the Lived Experiences of Self-Monitoring for Chronic Respiratory Care

Some of the data and findings from this chapter have been published as an extended abstract in the companion proceedings of the 2019 ACM Conference on Computer Supported Cooperative Work and Social Computing (*Tendedez et al., 2019a*)

6.1 Introduction

This chapter explores the lived experiences of self-monitoring COPD symptoms and sharing this personal health data remotely with healthcare professionals (HCPs). When HCPs and patients are both connected in the self-monitoring process, Bardram and Frost (2018) have called this as 'double loop' technology. This compares to 'single loop' technology, which only involves the patient in the self-monitoring process for their own self-management. I use an exploratory case study approach to uncover patients' and HCPs' experiences of engaging with a self-monitoring mHealth app,

designed for generating digital diaries about COPD symptoms. This chapter aims to answer the third research question: 'what is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals?'

The key contributions of this chapter can be summarised as:

1. Sharing personal health data remotely with HCPs can cause undesirable 'shifts' in the responsibilities of care between the patient and the HCP. These give rise to prominent accountability concerns for the HCPs.
2. The opacity of algorithms used within self-management technologies can cause users to distrust the technology as they struggle to understand its outputs.
3. Self-assessed data about COPD symptoms can be perceived as too 'subjective' to rely on for understanding a patient's symptoms and overall condition.
4. Technologies that give self-management suggestions to patients must align with the local healthcare organisations which support its use. Otherwise, the technology can become a source of conflict for patients.
5. Self-monitoring technology for COPD should offer personalisation capabilities to adapt to patients' individual needs and contexts, which may change as the condition progresses.

6.2 Study Setting

This study took place with a community care respiratory service (referred to as 'Community Care' henceforth), which is described in the methodology chapter (Chapter 3, section 3.4, pg. 50) and in Data Supported Decision-Making (Chapter 4, section 4.2.2, pg. 70). To recap, Community Care offer services that aim to support patients with COPD to self-manage their condition. The main aim of the service is to help patients avoid COPD hospital admissions through offering support within the

community. They provide a number of services including: intensive home support, pulmonary rehabilitation (PR) services, and patient clinics.

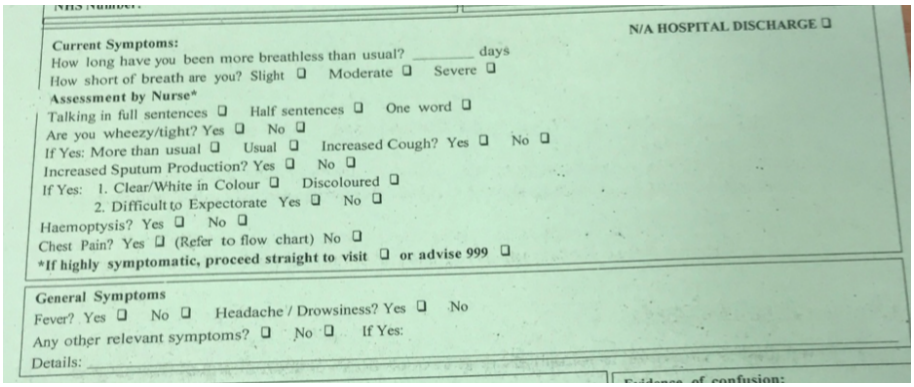
Intensive home support provides COPD patients with clinical support in their own homes, including home visits to check on the patient and provide them with medication and monitoring if needed. Patients may be on intensive home support services if they are acutely unwell or have recently been discharged from hospital after a COPD exacerbation. PR is an eight week group programme that consists of exercise, education, and breathing support classes. It is held at the Community Care site and requires patients to travel to the site twice a week to attend the classes. Patients are usually referred to PR after an exacerbation of COPD (which may have led to a hospital admission) or if the patient's General Practitioner (GP) believes they need support in learning about and managing their condition.

As Community Care provide support for COPD patients to self-manage their condition, they were interested in exploring new ways to support and educate patients. Particularly, they were interested in the role that digital technology could have for assisting patients to self-manage their condition and become better aware of their symptoms. They believed that the use of technology could alleviate some of the resource strains and pressures currently experienced by their service. Through providing a digital medium that patients could engage with to help manage their condition, they believed patients may become 'more empowered' and capable of managing independently. They believed mHealth apps were an inexpensive option to explore these motivations (Iribarren et al., 2017). They were familiar with, and wanted to explore using, the 'How Are You Today' app (described later in this chapter) as it was being used by other healthcare services in North West England.

6.2.1 Community Care

This section provides brief details on the daily work of the Community Care team. I spent half a work day (approximately four hours) at the Community Care site observing

their work practices. This was a context building activity aimed to learn about their working day in more detail. The nurses begin working at 8.30am when they start providing phone support to patients with COPD. They have a list of patients to contact on a spreadsheet and will typically spend all morning going through the list. They will contact patients registered on their service, such as patients on intensive home support or enrolled in PR. They also check on patients that have recently been discharged from the nearby hospital (described in Chapter 4, Data Supported Decision-Making, section 4.2.1 on pg. 69). They may receive phone calls from patients, and when they do, they typically structured their phone calls around a number of triage questions including asking the patient if they are short of breath, if they have increased sputum production, if they feel wheezy, and if they have chest pains (Figure 6.1). When calling patients, they will ask questions like *'how is your course of antibiotics?'*, *'have you had your nebuliser this morning?'*, followed by encouraging comments such as *'you need to give your medication more time'* and *'don't give up hope yet!'* A summary of each phone call is then recorded on the patients' electronic care record.


N/A HOSPITAL DISCHARGE ☐

Current Symptoms:
How long have you been more breathless than usual? _____ days
How short of breath are you? Slight ☐ Moderate ☐ Severe ☐
Assessment by Nurse*
Talking in full sentences ☐ Half sentences ☐ One word ☐
Are you wheezy/tight? Yes ☐ No ☐
If Yes: More than usual ☐ Usual ☐ Increased Cough? Yes ☐ No ☐
Increased Sputum Production? Yes ☐ No ☐
If Yes: 1. Clear/White in Colour ☐ Discoloured ☐
2. Difficult to Expectorate Yes ☐ No ☐
Haemoptysis? Yes ☐ No ☐
Chest Pain? Yes ☐ (Refer to flow chart) No ☐
***If highly symptomatic, proceed straight to visit ☐ or advise 999 ☐**

General Symptoms
Fever? Yes ☐ No ☐ Headache / Drowsiness? Yes ☐ No
Any other relevant symptoms? ☐ No ☐ If Yes:
Details: _____

Figure 6.1: The questions that HCPs will ask when answering phone calls from COPD patients.

Nurses will also discuss their case load informally in the office. They share important contextual information about patients to help the team improve their understanding of patients' individual circumstances (Weiner, 2004). For example, as well as discussing when a patient's last clinic visit was or their comorbidities, they

may discuss other very individual and contextual factors about a patient that affects their respiratory condition. For example, the temperature in a patient's house (which they know from home visits), when a patient's holiday is scheduled for, how many grandchildren the patient has, and which window in the patient's house they routinely keep open that produces too strong of a breeze. This important contextual information helps to paint a stronger picture of a patient's life so they can orient the support they provide. In the late morning (at approximately 11am), the nurses will then prepare for, and then conduct, home visits to patients that are on their intensive home support service. While this occurs, the physiotherapists and assistant practitioners will prepare for, and run, clinics or PR classes.

6.2.2 'How Are You Today' App

This study involved the use of an mHealth app called 'How Are You Today'[1] (referred to as 'the app' henceforth). The app had been commissioned by various National Health Service (NHS) respiratory services across North West England[2]. I was told by Community Care that the app was designed by HCPs and tested with patients. The app was based on pre-existing COPD paper diaries that were also designed by HCPs (see Figure 6.2). These paper diaries were offered to COPD patients in community care settings in North West England to support their self-management. To date, there is a lack of public information available about exactly how the app was designed and tested. The app's description on Google Play and the App Store simple states that it was created and tested with HCPs and patients. To the best of my understanding, this is the first systematic in-the-wild study that explores the app's use.

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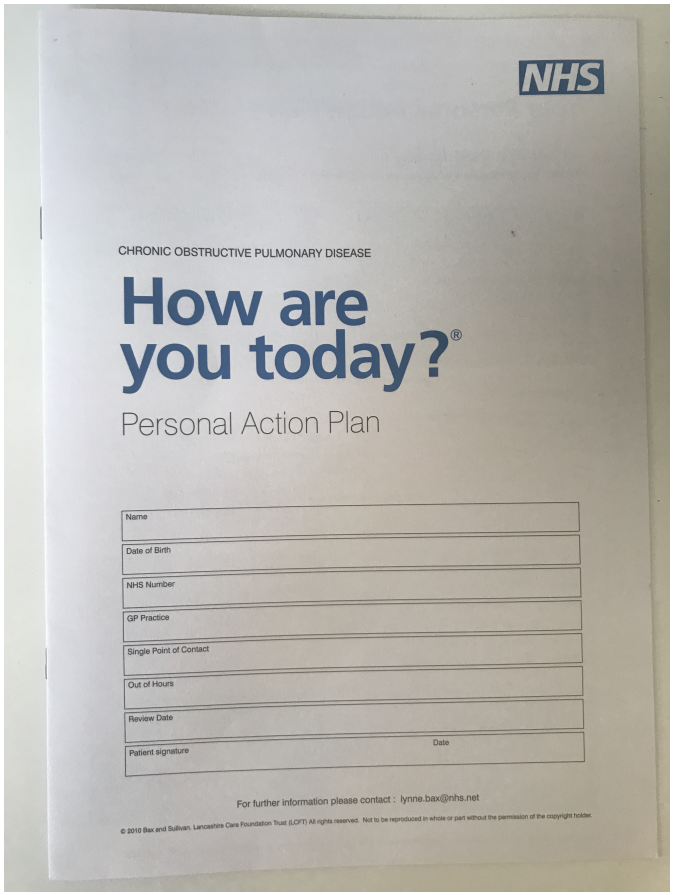
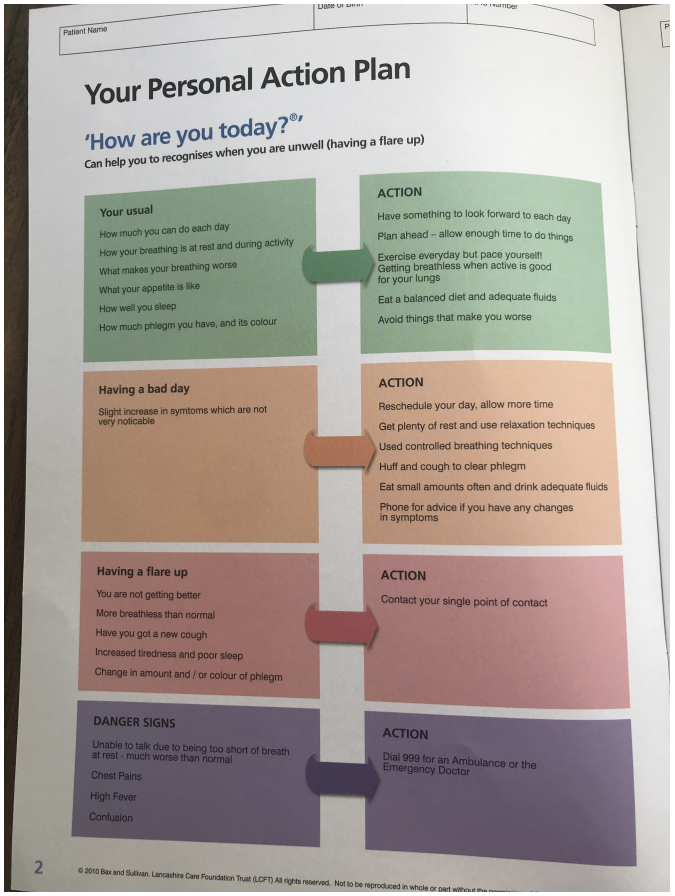
[1] 'How Are You Today?' Accessed February 6th, 2020 from https://play.google.com/store/apps/details?id=com.intelesant.copd&hl=en_GB.

[2] The How Are You Today app had been commissioned across healthcare services in North West England as it had been developed with, and by, HCPs working in this region.



(a) The front page of the paper diary.



(b) The types of days patients may experience and the action they should take.

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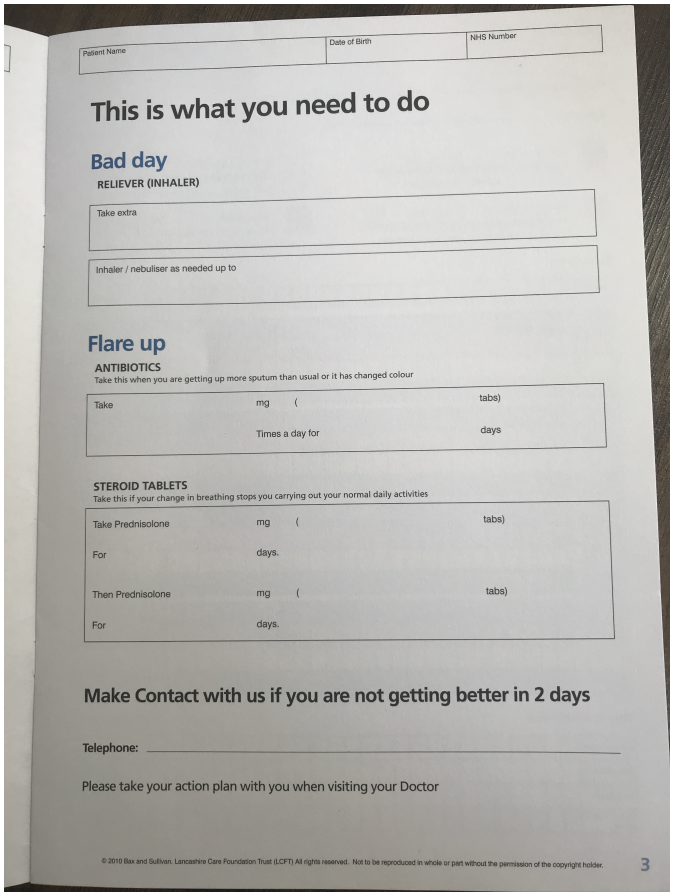
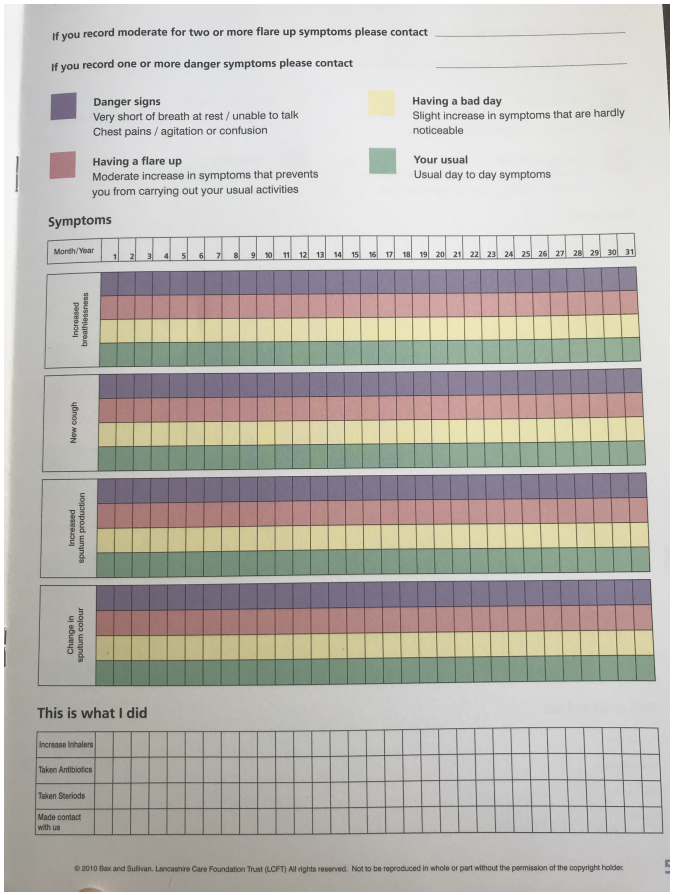
Figure 6.2: The paper based 'How Are You Today' diary.



(c) Patients can fill in medication related actions they should take during days where they face symptoms.



(d) The diary view where patients are asked to rate four symptoms against the day types.

Pictures included with full written permission from the copyright holders.

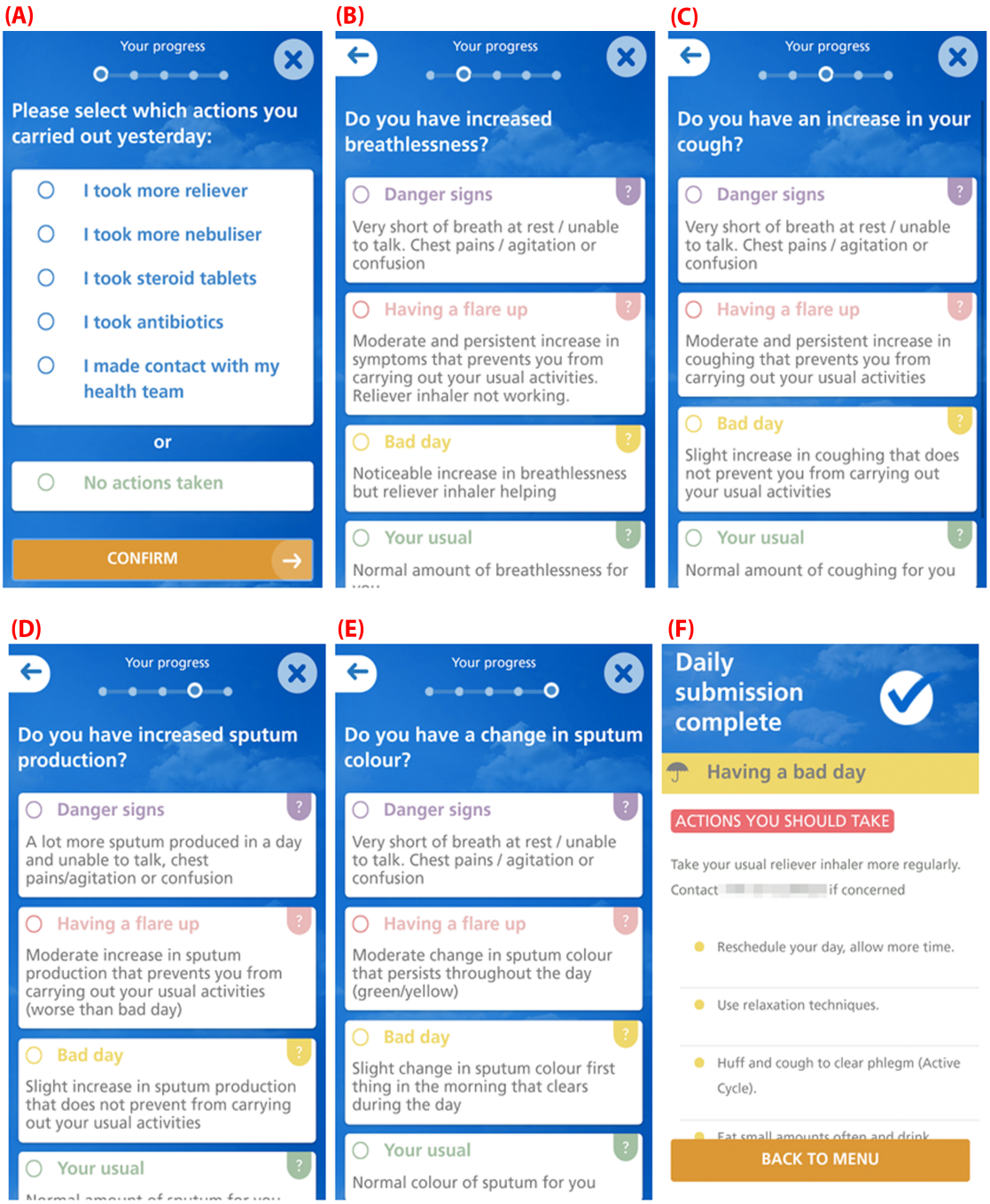
Figure 6.2: The paper based 'How Are You Today' diary (cont).

To start using the app, the patient requires a referral from their HCP. The app company then contact the patient and register them onto the app. This requires the patient to download the app onto their phone. After registration, the patient can start inputting symptom data, which is shared with their HCP as a weekly report.

Patients are required to fill out a short survey each day on the app, which consists of five questions (one action related question shown in Figure 6.3 (A) and four symptom related questions shown in Figure 6.3 (B-E)). The action related question asks the patient if they have taken any respiratory medication[3] on the prior day or contacted their healthcare team, then the four symptom related questions ask about potential increases in cough, sputum (phlegm) production, breathlessness, or changes in sputum colour. Once the patient completes the survey, the app labels the 'type' of day that the patient is having based on their input, and suggests a management action (Figure 6.3 (F)). There were four different day types that the app could categorise: 'no symptoms' (good day), 'bad day', 'flare up', and 'danger day'.

Typically in the event of a 'bad day', the app would recommend the patient increases their inhaler intake and contact their HCP if they feel concerned about their health. It will also provide tips to the patient, such as using relaxation techniques to improve the way they feel. During a 'flare up day', the app would suggest the patient makes contact with their healthcare service (the same service which referred the patient onto the app). It may also suggest that the patient needs antibiotics (e.g. if their answers indicate that the patient may have a respiratory related infection). Whereas in the event of a 'danger day', the app would recommend the patient to seek emergency support (i.e. call an ambulance). Each week a record of the patient's entries is securely sent to the HCP by the app company through a portal.

[3]Such as their reliever, nebuliser, steroid tablets, or antibiotics.



A-E detail the daily questions asked by the app.

F indicates an example daily suggestion provided by the app based on the user's answers to A-E.

Figure 6.3: The 'How Are You Today' app questions.

6.3 Study Design and Methods

This chapter reports on a three stage study with COPD patients and HCPs using the How Are You Today app. Patients were asked to answer the questions on the app every day for a period of 30 consecutive days. They were informed that if they had forgot to fill the app in one day, they could retrospectively answer the questions when they remembered (and if they wanted to). In other words, I did not ask patients to maintain strict adherence by filling in the app each day at the same time. During the study, HCPs were asked to review the patient-generated data weekly when it was sent by the app company. They were only asked to engage with this data in the same way which they would outside of the study's context. That is, they were not required to do anything specific with the data as part of the study.

Qualitative data was captured from both HCPs and patients through one-to-one interviews, phone calls, and focus groups. I collected data from the HCPs twice during the study, first at the beginning (a focus group exploring their motivations for the study) and then at the end (interviews to understand their experiences on the study). I collected data from patients three times during the study, first at the start of their involvement on the study (an interview that explored their motivations and expectations for the study), then a short phone call with them halfway through their time on the study (to check in on how they were getting on with the process of self-monitoring), and finally at the end of their 30 day self-monitoring period (an interview to understand their experiences on the study). Though the app company were not explicitly involved in this research, they were aware of the study, as Community Care contacted them about using the app for a pilot study. They agreed to provide basic information about how many diary entries the patients' made throughout the study (so that I could review their engagement with the app when interpreting the findings). However, I did not have access to the patients' diary entries.

Patients were informed that they were free to continue using the app after the study, or had the option to delete their account and uninstall the app. Deleting their

account would lead to the deletion of the data generated throughout the study[4]. They were informed to contact the app company if they required any support about the app beyond the study.

6.3.1 Participant Recruitment

The following sections describe the process undertaken to recruit the HCPs and patient participants onto the study.

6.3.1.1 Healthcare Professional Recruitment Process

Four HCPs were recruited onto this study (Table 6.1). Three of them (NURSE, PHYSIO, AP1) were already known to me through their involvement in Chapter 4 (Data Supported Decision-Making). The fourth one, AP2, was invited to participate by NURSE, due to their involvement with COPD patients through running and assisting PR classes. The HCPs all had direct involvement with the care of COPD patients within the Community Care service. PHYSIO is the lead physiotherapist at Community Care, they are highly experienced and manage a team of physiotherapists, lead PR classes, and run one-to-one physiotherapy clinics. NURSE is a lead COPD nurse, they are highly experienced in their role and manage a team of specialised COPD nurses. They also run spirometry clinics (where patients are given annual or diagnostic spirometry tests), nurse clinics (where patients receive specialised management support), and conduct home visits and phone calls to patients. AP1 and AP2 are assistant practitioners, they assist the running of PR classes, educate patients about managing their condition, and more generally support the wider healthcare team where needed.

[4]This was arranged through the app company and I had no involvement in this process. This was the standard process for any patient using the app, whether on this study or not.

Participant	Job Role
NURSE	Lead COPD Nurse
PHYSIO	Lead Physiotherapist
AP1	Assistant Practitioner
AP2	Assistant Practitioner

Table 6.1: Chapter 6 HCPs participants.

6.3.1.2 Patient Recruitment Process

This study involved recruiting COPD patients from Community Care's PR programme. The HCPs explained that patients on their PR programme were a good target group for the study, as they were already receiving education and support to help them self-manage their condition. Therefore, it was thought that these patients would be motivated to participate in the study as they were currently learning about, and working on, ways to better self-manage their condition. Patients that expressed interest in the study were provided with an information sheet with my contact details, and were advised to contact me if they wished to participate (see Appendix K). Patients required access to a smartphone and the internet to download and use the app.

Recruitment was open from May to November 2018. As discussed in detail in the methodology chapter (section 3.5.1.2, pg. 55), patient recruitment was very challenging for this study. The HCPs approached eligible participants in clinics and at the start and end of weekly PR classes. As PR was an eight week rolling programme, HCPs would only encounter new patients every few weeks. Therefore, they did not have the opportunity to approach new eligible patients on a daily or weekly basis. In the end, four patients contacted me to express interest in participating.

6.3.1.3 Patient Participants

A total of four COPD patients (three men and one woman) were enrolled onto the study (Table 6.2). The first patient was recruited in August 2018 and the last in October

2018. All patients were enrolled in the PR programme at the time of their recruitment. They all had their own smartphones and internet access for the study, except Chris, who was loaned a smartphone and SIM card with 5GB of data (see Chapter 3, section 3.5.1.2, pg. 56). Once each patient contacted me to express interest in participating, I met with them to take their full informed consent, and then proceeded to interview them. After this, I informed the HCPs by email that I had enrolled the patient onto the study. The HCP then contacted the app company to provide them with the patient's contact details to set them up on the app (following the standard referral process). The app company registered the patients onto the app between one and six days after their enrollment on the study. After this time, the patients could start inputting their symptom data onto the app.

Participant	Age	Gender	Diagnosed	Comorbidities
Petros	66	Man	1 year	Abdominal hernia
Robert	65	Man	1.5 years	Suspected heart condition
Lia	68	Woman	10 years	None reported
Chris	76	Man	16 years	Bowel cancer

Table 6.2: Chapter 6 patient participants and their assigned pseudonyms.

6.3.2 Exploring Healthcare Professionals' Motivations

The first method of data collection for the study was a focus group lasting 36 minutes with NURSE and PHYSIO. The aim was to understand their motivations for introducing a COPD self-monitoring app into their service. I asked questions such as: *'in what ways can the introduction of a self-monitoring app for COPD benefit your patients?'*, *'in what ways can the introduction of a self-monitoring app for COPD benefit your service and your staff?'*, and *'does the introduction of a self-monitoring app for COPD support your organisational goals?'* I chose to capture this data through a focus group to draw on the HCPs' joint expertise and experience of working in Community Care,

followed by providing the opportunity for them to learn about one another's thoughts and perspectives. It was not possible to coordinate a time where AP1 and AP2 were also available, so I prioritised collecting this data from NURSE and PHYSIO who were senior HCPs. The focus group insights were used to prompt the questions in the follow up interviews later in the study, scoping whether expectations had been met.

6.3.3 Exploring Patients' Motivations

I conducted one-to-one interviews with patients at the start of their involvement on the study, lasting between 30 and 60 minutes each. The interviews sought to understand their experiences of self-management, expectations of using technology to self-monitor their symptoms, and expectations of sharing this data with HCPs. I met participants in their homes or after their PR classes (at the Community Care site) for their convenience. I informed patients that they could have a family member or carer present during any interviews if they wished, and only Chris chose to include his wife. Chris' wife was heavily involved in his care, and also contributed to the interview data (with full informed consent). After the interview had occurred, I showed participants how to download the app and talked them through how to use it. I also provided them with written instructions.

6.3.4 Checking in with Patients

I had prearranged a call with each patient after approximately 14 days of them having used the app, to check in on how they were finding the experience of self-monitoring and to answer any questions that they may have[5]. The discussion centred around one main question which was *'so far, how are you finding the experience of monitoring*

[5]Patients were made aware that they could contact me at any time during the study if they had any questions. However, nobody did.

your symptoms each day'? Phone calls lasted between 5 and 15 minutes, and were not audio recorded. Instead, I made detailed notes during and after each phone call. During the calls, I also asked patients to schedule their concluding interview on the study (to occur approximately 14 days after the phone call took place).

6.3.5 Understanding Patients' Experience

30 days after the initial interview, I conducted a final interview with patients to understand their experience of self-monitoring each day. I met Chris and Robert on the 30th day of them monitoring themselves using the app. However, I could only arrange to meet Lia 10 days after the 30th day elapsed and Petros 30 days after the 30th day elapsed due to practical reasons (Lia had been away on holiday and Petros was hospitalised). However, all patients had been self-monitoring up until the day they were interviewed (they had freely chosen to do this). I met Robert, Chris, and Lia face-to-face for the interview, either in their homes or after their PR class for their convenience. However, I conducted the interview with Petros over the phone as he was unwell and felt more comfortable with this option. Petros had still been using the app up until the concluding interview (thus he was not recalling his experience of using the app from over 30 days ago). I asked the patients questions such as *'how would you describe your overall experience using the app to self-monitor your condition?'*, *'how did you interact with the app throughout the study?'*, and *'would you consider using a mobile health app in future to manage other aspects of your health?'* Interviews lasted between 30 and 90 minutes.

6.3.6 Understanding Healthcare Professionals' Experience

Once each patient had concluded their involvement in the study, I conducted follow up interviews with each HCP (Table 6.1) to learn about their experiences supporting patients' use of the app and receiving personal health data generated by them. I also explored challenge areas about the study to the HCPs, such as recruitment difficulties.

Interviews were held at the Community Care site, and lasted between 30 and 45 minutes each. Interviews were held in January and February 2019, which was a challenging season[6] for the HCPs due to the increase in patients with COPD that are unwell and require support. Hence, it was difficult for HCPs to find availability for the interviews. It would not have been practical to delay the interviews until HCPs had longer periods of availability, as I wanted to ensure HCPs could recall their experiences of the study as accurately as possible. I asked questions such as *'how did you find the study overall?'*, *'how did you engage with the weekly patient reports?'*, *'what have you learnt from being involved this study?'*, and *'were there any specific benefits or drawbacks you found as part of the study?'*

6.4 Findings

The following sections present the findings from both the patients and the HCPs. The first two sections discuss the patients' and HCPs' motivations for the study, with the final sections focusing on their experiences on the study.

6.4.1 Healthcare Professionals' Motivations

The following two sections describe the HCPs motivations to introduce a self-monitoring app into their service, arising from the focus group held with NURSE and PHYSIO. These motivations are divided between 'Organisational Benefits' and 'Individual Patient Benefits' and are described in detail below.

[6]NHS winter pressures are reported to last between November to March every year (Fisher and Dorning, 2016).

6.4.1.1 Organisational Benefits

The HCPs discussed that introducing a self-monitoring app for COPD within their service provided a way that they could give *"the patient the autonomy and the empowerment to manage their condition"* (NURSE). Teaching and promoting self-management is a core priority for Community Care to support patients in living with their chronic condition. NURSE and PHYSIO both discussed how the organisation were looking to improve how self-management is promoted and sustained among the various different COPD patients that engage with their service, as they believed that they needed to adopt a more *"proactive"* (NURSE) approach to help those patients who engage less with their service but still require support.

For example, they recalled how they used to offer a three month review to patients after they have completed PR to check in on their self-management, but found that *"it's kinda a waste of time"* (PHYSIO) as *"the patients who comply and do well come, the ones who don't, don't"* (PHYSIO). In light of this, they were undertaking *"quite a lot of development work"* (PHYSIO) in how they run their PR programme as a starting point. This included restructuring the sessions and the content within the sessions, and following up each week with patients to reinforce the lessons learnt in the previous week. For this reason, PR was thought to be a *"really good place to get something like that [the app] instigated"* (PHYSIO) as *"you're seeing the patient then for six weeks"* (PHYSIO). This face-to-face contact could help familiarise patients with the HCPs, who could in turn encourage them to engage with self-monitoring during a period where they are enrolled into a programme focused on enhancing self-management techniques.

In addition to this, using an app was perceived to be a less *"expensive"* (NURSE) and thus a more accessible approach to support patients in self-managing, compared to telemonitoring practices whereby the organisation provides equipment to patients

in their home[7]. NURSE described how the HCPs could *"look at data over the phone, and if the patients saying they don't require a visit from us at least we've got some kind of back up in the sense of knowing that"*. This was thought to be an another area where the app could support reducing resources where appropriate.

6.4.1.2 Individual Patient Benefits

There were also benefits that the HCPs believed self-monitoring could bring to individual patients on their service. Specifically NURSE discussed how *"patients who are newly diagnosed or quite early in the disease"* could benefit from learning *"to understand the implications and the symptoms and deterioration"* of their condition through the process of self-monitoring, as *"quite often patients are unaware of their symptoms until they start to use technology to identify when things are getting worse"* (NURSE). For PHYSIO, the process of self-monitoring would help the patient in *"learning to look after yourself and manage your condition better"* through reflecting on the symptom data each day as *"patterns of self-reporting is useful, trends, and being able to see whether it's something new that day or actually has this been going on for a few days"*, and *"it [the app] does prompt them"* (PHYSIO) to take appropriate action.

Though the HCPs felt the app was primarily *"a self-management tool that is for them to identify when they should be ringing us"* (NURSE), HCPs could *"identify patients that don't like to bother us, they leave things until it's too late ... there's this kind of understanding that from a certain cohort of patients that they're bothering us or they don't think it's appropriate to ring us"* (NURSE) and that these patients could be supported and *"managed earlier"* (NURSE) if there was a way of better identifying them through the *"weekly patient reports"* (NURSE).

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[7]Telemonitoring has been described as 'the use of communications technologies to monitor and transmit items related to patient health status between geographically separated individuals' (Maric et al., 2009).

Both NURSE and PHYSIO discussed being eager to hear the *"patient experience and what they'd want on it if we were to change it [in future]"* (NURSE) so they could decide *"whether or not we continue with the app or move on to something else"* (NURSE) that could provide self-management support to patients.

6.4.2 Patients' Motivations

The two sections below describe the patients' two key motivations to engage with self-monitoring and to participate in the study, which was collected through the four interviews with the four patients on the study (Petros, Robert, Lia, and Chris). The two key themes that patients discussed as their reason for participating in the study are (1) 'sharing data with healthcare professionals' and (2) 'self-monitoring for self-reflection'. These are described in detail below. Petros and Robert described themselves as being confident with technology, having worked in the information technology sector in the past. Lia described herself as moderately confident in using technology. Chris described himself as having a low level of confidence in using technology.

6.4.2.1 Sharing Data with Healthcare Professionals

The main motivation described by patients to engage with the self-monitoring process was to work with HCPs to optimise their self-management strategies. Having the HCPs involved in the monitoring process was perceived to be *"putting another arrow in your bow"* (Robert) in the process of managing a progressive chronic condition, and *"rather than saying 'oh I'll try this, I'll try that"'* (Robert) they can be better *"guided"* (Robert) by the HCPs. For example, collaboratively analysing the data and identifying *"trends and how you've got around it [difficult periods], and see what works and what didn't work"* (Petros) because *"every person is different, their lifestyle, the weather, their home, their diet, and drinking, whatever the case may be"* (Chris) and better understanding these individual factors can help in the process of creating more effective self-management plans.

Patients also believed that being connected to their HCPs through the self-monitoring process would help them obtain timely help in the case of health decline, as *"we only tend to contact them when we go to [PR] class"* (Petros) or, outside of the PR programme, *"once a year to see how you are getting on with the nurse"* (Chris).

For patients, sharing self-monitoring data and viewing trends could help obtain the support needed outside of those periods as *"sometimes if you're not feeling *too* bad you're reluctant to ring up ... whereas if they are getting feedback of how I've been over the week, maybe they might see something"* (Petros) and help to overcome situations where *"I didn't feel confident enough to say 'I'm really poorly'"* (Chris). The collaborative approach of collecting symptom data and sharing this with HCPs for decision-making was thought to be important, as Lia believed that it would be *"a bit pointless"* if HCPs were not connected in this process to incorporate their perspective of the generated data. Likewise, Robert believed collaboration between the HCP and patient is needed to create and alter self-management strategies as if it is *"just done by the nurses then you're talking down on the patient, and their motivations are not taken into account"* yet *"if the patient is doing it by themselves, then they are not taking note or they're not taking on board the professional advice which is available."*

6.4.2.2 Self-Monitoring for Self-Reflection

Self-monitoring to aid the process of self-reflection about symptoms was the second motivation highlighted by participants. This reflection process was thought to help patients in being able to personally adapt their strategies for self-management as a response to the insights provided by the self-monitored data. They had acknowledged the limitations that their condition placed on their lives, and expressed being willing to engage with different types of research conducted by their healthcare organisations if it could *"help in any way shape or form"* (Lia) as *"I want to be able to improve my COPD"* (Chris). For example, Lia described how having a diary of her symptoms *"might make me more aware of actually recognising when there's any differences [in the*

days], and make me think twice before I do nothing about it like last time." Likewise, Petros was motivated to use the app to reflect on his symptoms over time, comparing this to how he began using Fitbit to track his steps and sleeping since they became effected by his COPD. Whereas Robert discussed that he could use the data collected over time to make correlations with his symptoms and his behaviour, such as *"the weather is such and such, I must take medication, or if I'm going to do a certain activity, take medication before or after I do it ... but that will come with time."*

In addition to the perceptions of being able to adjust self-management behaviours to manage symptoms, Chris and Robert discussed hopes that insights from their data could help them to restore their health in the instance of a flare up without the need to take extra medication. For example, Robert described his approach to taking medication as follows *"I tend to take it when I need it, the medical professionals say 'no you carry on with it', but I think I know my body better than somebody writing prescriptions"*. Both Chris and Robert raised concerns about taking antibiotics in response to exacerbations[8], noting *"I don't like taking antibiotics because next time will that antibiotic work as well as it should? ... *are* they the solution?"* (Chris) and *"I don't want it [antibiotics], personally my body can cope without it ... If it was spreading and I can't breathe and this that or the other, yeah then I'll pop in and ask for help. But otherwise I feel it's unnecessary, that's my personal reasoning"* (Robert). They both raised the perception that it is important to try different strategies to deal with a flare up before resorting to taking antibiotics, as they had concerns about the health effects and possible resistance.

[8]Recall that during periods of exacerbations a patient may be prescribed antibiotics, as discussed in Chapter 2, section 2.1.1, pg. 17.

6.4.3 Healthcare Professionals' Experiences

The HCPs noted that patients engaged well with the app, even approaching the HCPs at the PR classes saying *"'I've filled my app out today', they wanted to tell you about it, 'I've had two good days!'"* (AP2) and that at the time of the interviews with the HCPs, they noted *"the reports that we are getting in now show they are still filling it in"* (AP2). The following sections describe the key themes which arose from the analysis of each interviews with the HCPs (NURSE, PHYSIO, AP1, and AP2) where they reflected on their experiences on the study. There were five main themes identified from the thematic analysis: (1) 'concerns around failure to act'; (2) 'concerns around overreacting'; (3) 'misalignment with local practice'; (4) 'opacity of the app's algorithm'; and (5) 'blurring of role boundaries'.

6.4.3.1 Concerns Around Failure to Act

The simple action of receiving patient-generated data around daily symptoms created a feeling of a *"professional obligation to act on that [data]"* (NURSE) for the HCPs, which is *"one of the issues with that sort of data"* (PHYIO) that is sent to HCPs remotely and *"there'd be the expectations that you were checking it"* (PHYSIO). They had perceived themselves as implicitly accountable for taking immediate action based on the weekly reports that they were sent.

This led to them disengaging with viewing the reports after the second week of the first patient being enrolled, and would only access the data if *"somebody rang in and then we could refer to it and have a look at their data"*[9] (PHYSIO) or *"when we've got time really ... [as] every bit of our day is planned up"* (AP2). This arose from concerns that patients may depend on them to immediately detect and subsequently act on any signs of health decline surfacing from the data. NURSE highlighted the

[9]They informed the patients of their decision to do this.

difference between telemonitoring and the app, which was *"more a self-management tool"*, yet receiving the patient-generated data on the app blurred the boundaries between telemonitoring and self-management and made them feel that they *"should be"* checking the data consistently.

For example, NURSE mentioned that if the reported data *"doesn't go anywhere [i.e. automatically to the Community Care service]"* then it better facilitates self-management as the patient is *"responsible"* to make necessary contact with their healthcare team and could optionally share data at that point. This was echoed by AP1 who felt that if the data is being sent to the HCPs then there must be some sort of action required on their behalf: *"it's like doing somebody's blood pressure and it being raised and not acting on it, isn't it? It's like what is the point in having done the blood pressure in the first place if you're not going to do something with that information?"* Whereas AP2 described viewing the weekly data and seeing that one patient had not input for a few days, and had *"wonder[ed] why they've not filled it in"* and felt that it could be a cause for concern, but when contacting the patient they had been *"struggling logging in"* to the app, hence the lack of entries. AP2 highlighted that the potential concerns around missing reports is *"something to think about"* in future discussions around how HCPs should respond to missing data entries, as it could lead to HCPs needing to make contact with the patient. This was noted as being unfeasible at scale, and even with the four patients on the study, was *"generate[ing] more work for the team"* (NURSE) which the app was meant to alleviate.

6.4.3.2 Concerns Around Overreacting

The HCPs voiced how continuous symptom monitoring using only subjective scoring could lead to both themselves and patients overreacting to the data. For example, it was highlighted that breathlessness was rated by the patient subjectively on the app without any objective measurement, such as a pulse oximeter reading. This had implications for the consistency of the patient-generated data as a whole. PHYSIO noted that two patients with similar levels of breathlessness *"could give you two*

completely different answers" when being asked to rate *"breathlessness from one to 10"* as *"their perception of how unwell they are is very different and that effects things"* and *"that could lead to us needing to visit more patients which isn't a bad thing but then that increases demand on service because that patient doesn't have the equipment to check their own [vital] signs"* (NURSE).

It was further noted by the other HCPs that it is not uncommon for COPD patients to mistake feelings of breathlessness as a flare up of their condition. For example, patients may perceive breathlessness caused by anxiety or tiredness as a worsening of their COPD symptoms, and it is important to distinguish *"are they feeling not so good today from a medical point of view or an anxiety point of view ... they might have seven bad days but they are not unwell, that's just their condition ... what distinguishes from a bad day when you've got a long-term condition?"* (AP2) and *"something that would allow some sort of identification of baseline"* (PHYSIO) would generate more reliable data, or justification of the rating such as *"if there was an opportunity where they could say 'increased sputum' or 'shortness of breath on exertion' you know there doesn't have to be war and peace, just something to justify the X"* (AP1).

When this distinction was faced in regular clinical practice, the nurses would coach the patients over the phone to better recognise the root cause of their breathlessness and reassure them that they are not experiencing a COPD exacerbation because *"using an inhaler isn't going to help somebody who is anxious"* (AP1). However, the app relied solely on the patients' subjective measure of breathlessness and would label the day type accordingly. The HCPs would not be able to distinguish the cause of the breathlessness from the data alone, and felt accountable to immediately follow up with the patient.

Moreover, it was noted that the suggestions from the app may further cause patients to believe they are exacerbating, which can be *"quite a frightening thing"* (PHYSIO) and may trigger *"more anxiety"* to the patient (PHYSIO). For example, AP2 noted that the app would still reflect that the patient may be exacerbating when they are recovering from a recent exacerbation as *"it takes longer to recover, so if they are then putting in more bad days but they've just been on treatment, would it then say*

you need more treatment when actually they're just having bad days because they have an infection?"

In addition to this, NURSE and AP2 reflected on how the app was reported to use the term Ventolin (the brand name of the inhaler medication Salbutamol), which caused confusion as one patient phoned Community Care concerned, stating *"it's telling me to take my Ventolin but I don't have Ventolin, I'm on Salbutamol, so do I need this new inhaler?"* (AP2) and having to tell the patient *"no, actually what you are on is correct, it's just using a different [drug] name"* (AP2).

6.4.3.3 Misalignment with Local Practice

The daily recommendations that were generated by the app were highlighted by HCPs as lacking alignment with the *"model of management"* (PHYSIO) in their local Community Care practice. They noted how the app provided generic management advice to patients, when their approach was to *"individualise care"* (PHYSIO) depending on patients' lifestyle, condition stage, and particular needs. PHYSIO expanded on this by stating the advice from the app was *"too simplified"* and that *"there's [national] guidelines but that will be implemented individually to the patient"*.

For example, advice on frequency of inhaler[10] use was noted as being specific to each individual patient, where they *"would be advised on an individual basis in what circumstances to take their inhalers"* (PHYSIO) with some patients *"advised to use them on a regular basis"* (PHYSIO) and some advised to *"use them when needed"* (PHYSIO). Additioally, *"somebody might take one puff twice a day of a particular inhaler"* (PHYSIO) and *"another person will have two puffs twice a day"* (PHYSIO) and *"you can't give standard advice even about that"* (PHYSIO).

[10]Be reminded that the app might suggest for the patient to increase their inhaler usage when reporting certain symptoms (see Figure 6.5 (F)).

Therefore, PHYSIO noted *"I've got a reluctance or scepticism about that sort of advice being generated by an app."* Likewise, AP1 and AP2 felt that the app focused more strongly on medication specific actions when *"there's not always a medical solution, it could be a therapeutic one initially [before resorting to increased medication use]"* (AP1) such as asking the patient *"have you tried your breathing techniques?"* (AP1) or *"the use of different [body] positions"* (PHYSIO) before *"just relying on medication"* (AP2). It was acknowledged that the app did provide therapeutic tips with daily reports, but these were not presented as headline actions for the patient (whereas the medication suggestions were, see Figure 6.3 (A)). Whereas NURSE was concerned that the app suggested to patients that they may need to take antibiotics[11], and could result in patients who have rescue packs[12] at home who might *"initiate that treatment"* too quickly at the app's suggestion or *"patients who would go 'alright I'll go get some' [medication]"* (AP2) and visit their GP. The challenge associated with the misalignment of the app's advice and local practice led to a patient calling Community Care to establish which guidance to follow. As such, HCPs had to verify which advice to follow. This was thought to be *"doubling up on work"* (AP1) that HCPs have to do, and causing the potential for patients to get *"confused"* (NURSE) about their management advice.

6.4.3.4 Opacity of the App's Algorithm

The HCPs also raised concerns around the opacity of the algorithm used to generate the daily suggestions to patients. NURSE highlighted that as *"we [Community Care] weren't involved in that process"* of designing the algorithm and agreeing on *"the*

[11] Recall that this would be suggested on a 'flare up day'.

[12] A rescue pack is a small supply of steroids and antibiotics that COPD patients keep at home for use when a flare up occurs. Whether a patient is issued them or not is at the discretion of the HCP and local practice guidelines.

wording" of the recommendations, they were less *"confident"* in the daily suggestions and as such, less confident in recommending the app to patients. Likewise, PHYSIO described that being part of the design of the app would make *"you more engaged [with it] because you've actually got a stake in it, you've been involved in the setting up"* and can vouch for its validity and robustness.

AP1 and AP2 acknowledged that the app was created by HCPs but stated that *"we don't know what the algorithm is or what it does"* (AP1) and queried *"when was that algorithm developed? Is it [based on] old information?"* (AP1). Their concern was that *"advances in medical science"* (AP2) may not be reflected in the app, as *"everything has changed, inhalers have changed haven't they? Techniques have changed"* (AP2) and they were uncertain that the algorithm was kept *"up to date"* (AP2).

For AP1 and AP2, knowing what HCP had developed the algorithm and knowing *"it had come from someone related to respiratory"* (AP2) with *"a specialism"* (AP1) would have given them *"more confidence in it"* (AP2). It was clear that as the HCPs were not aware of how the algorithm worked and what evidence it was based on, their confidence in its outputs were compromised. Moreover, a lack of confidence in how the app works meant that that HCPs *"are going to be less confident in promoting it to patients"* (PHYSIO), and *"if we're going to do something like this in future, then that would be the first thing to make sure everyone is fully on board because then if they are they're confident promoting it to patients"* (PHYSIO).

6.4.3.5 Blurring of Role Boundaries

One notable problem (faced mostly by the assistant practitioners) was having to answer patient queries about the app, both technical and medical. For example, as AP1 and AP2 were primarily involved in patient recruitment for the study, when patients faced a problem with their daily suggestions or using the app, they would call or approach them specifically for help as *"in their mind the only person to contact would be us because we recommended it [the app] ... [they presumed] we've created it and if there was a problem we'd sort that out"* (AP2). This was an unintended

consequence of the study, and patients were made aware initially that they should contact the app company for all technical enquiries (e.g. difficulties logging onto the app or using the app). However, one patient approached AP2 for support logging into the app, noting *"obviously we would always help them, but when they couldn't log in, and stuff like that, that was nothing to do with us, but then we ended up helping them with that"*, which was challenging as *"it's more work for us ... we're already stretched."*

Patients were also asking the assistant practitioners for medication advice over the phone, which was challenging as assistant practitioners are not *"not medication trained"* (AP2) and *"luckily there was a staff nurse next to me"* (AP2) to answer the patient's question, but there *"needs to be more defined boundaries as to who is responsible"* (AP1) to reassure patients over the phone and answer their queries. Overall, with having to deal with technical questions about the app and advice on the daily suggestions created a situation with the assistant practitioners where *"something that necessarily wouldn't be our role had turned into our role"* (AP1). AP1 argued that to support such an app in future practice, a HCP that is qualified in providing medication support will need *"protected time to go and review the data"*, whereas NURSE supported this viewpoint by stating that it needs to be clear what type of HCP is suitable *"to interpret that data"* generated by the patient.

6.4.4 Patients' Experiences

The following sections combine the data from the interviews with patients (which occurred after 30 days of them using the app) and the phone calls with them (which occurred approximately 14 days into their use of the app). A total of eight themes arose from the thematic analysis, which were condensed into five themes: (1) 'engaging with self-monitoring'; (2) 'personalising questions and suggestions'; (3) 'applicability of questions and suggestions'; (4) 'uncovering insights in reported data'; and (5) 'monitoring as a safety net'.

According to the data from the app company, the levels of engagement from the patients during the 30 day period were as follows: Petros monitored 25/30 days, Robert monitored 30/30 days, Lia monitored 29/30 days, and Chris monitored 27/30 days. These can be considered relatively high levels of engagement. Recall that Petros and Lia monitored beyond this 30 day period, as they were voluntarily continuing to self-monitor up until their final interviews. Therefore, although the original aim of the study was for patients to recall their experiences of self-monitoring for a period of 30 days, their experiences detailed below are indicative of a longer period of engagement.

6.4.4.1 Engaging with Self-Monitoring

Patients reported a positive overall experience using the self-monitoring tool, but noted that the process *"would bring more benefit"* (Lia) and be more *"valuable"* (Lia) during more challenging periods, such as during bad weather or flare ups. All patients described filling in the app once they *"felt it was right to fill it in, as to what my expectations of the day was or has been, rather than just going through the process of filling it in"* (Robert). Patients described needing time *"to let the whole day pass before you can really judge [your symptoms]"* (Lia) and think *"about it, what I'd actually done, what I'd actually achieved"* (Chris) to provide a true indication of the day. This meant that patients typically filled in the app in the late afternoon or evening. However, for Petros and Robert, when they filled in the app did vary depending on the severity of their symptoms. For example, Petros reported that when his symptoms are bad that he will fill the app in at a later time, as he would be too preoccupied dealing with his shortness of breath. Whereas Robert reported the opposite, stating that if he felt particularly symptomatic he would be reminded to fill the app in *"very early"*, and use the suggestion to plan his day.

There were occasions where patients forgot to record their symptoms on the app, and suggested the use of reminders to help them to remember. Periods when patients forgot to fill in the app were usually during busy days and holidays, where

they *"had better things to do"* (Lia) than take their mobile phones out and reflect on their condition. The ability to provide delayed reports was perceived as useful so that patients could return to the app once they had remembered, which all patients had experience of doing. However, for Petros, he had not filled in the app for one week due to being acutely unwell and having a respiratory related hospitalisation. He had highlighted that completing reports retrospectively when unwell was challenging, as *"you've got to remember what it was like... what did I take [medication wise]?"* on the previous days, and *"if you've not done it for a few days, then you don't remember what you were last like"*, and as he *"lapsed so much, it affected how much I used it"* as it was difficult to pick up where he had left off.

6.4.4.2 Personalising Questions and Suggestions

All patients described that they would prefer more personalised questions to be asked by the app, with a strong emphasis on personalised feedback in the daily suggestions. For some patients, desire for personalisation seemed to become more apparent as their time on the study increased, as Petros described how *"at first it met my expectations but as I said you don't get any personalised feedback ... I started filling it in and it was okay, but then I just found it a little bit laborious for one thing, you're putting the same thing [each day]"*, while Chris stated *"it just needs more answers in there [in the daily suggestions] that say 'well stop doing this!' That becomes a bit more personal then, doesn't it?"* Robert described how *"a generalised app would be mundane"* and that he wanted *"an app for Robert, not for Mr X"*, that is *"reactive"* and not *"pre-written and one message applies to all"*, but in the same way that *"the conversation we are having now is a reactive conversation, I'm making a statement and there's a response forthcoming, and the whole response is relevant"*.

One of the main reasons that personalised questions and feedback was felt to be important was due to the fact that COPD *"gradually gets worse, so the app needs to be personalised and change, and help people manage their condition so it doesn't get worse"* such as *"whereby the app would recommend this person is on*

such and such of a dosage, that would indicate how bad that particular person is and it would be geared towards that" (Robert). Whereas Lia, Chris and Robert noted that COPD symptoms are heightened under certain circumstances, such as being exposed to *"alternate surroundings or atmospheres"* (Lia) or the *"weather ... if it's damp or wet outside"* (Chris), and certain *"activities"* (Robert), which should be factored into the daily questions and subsequently the daily recommendations. One way that the suggestions could become more personalised and useful is *"filling it in twice a day ... when you start your day off ... then you would fill it in again, and it would review whether it was correct or not and it makes self-improvements"* (Robert). By doing this, the app may begin *"predicting what kind of treatment or activities I should be doing for that particular day"* (Robert), or say *"look you're still poorly, call an ambulance, or call your COPD nurse or specialist, you can perhaps help yourself a bit more better"* (Chris) as Chris' wife mentioned *"it's no good saying with him sit down, because that's what he's doing most of the time anyway"*.

6.4.4.3 Applicability of Questions and Suggestions

Patients had some concerns about the perceived applicability of the app's daily questions and suggestions. Lia, Petros, and Chris reported that the app's questions, and in some cases suggestions, did not feel applicable to them individually. For example, Lia discussed that the question that asks about *"the change in sputum colour ... that only applies if you manage to cough it up, because that's the only time you see the colour, it's quite difficult to actually say"*, which meant that she could not often tell if her sputum had changed colour in order to answer the question accurately[13]. She also discussed perceiving expectoration as a positive sign for her, contrasting with how the app portrayed it to be negative, by stating *"suppose some people would describe that*

[13]It may be the case that Lia would be expected to select that this was 'normal' when picking her answer, but it evidently was not communicated clearly to her.

as a bad day in a way, but actually it's a good day because it's getting rid of the damn thing ... I'd call coughing up good not bad [discussing how the app labels this as a 'bad day']".

When reflecting on her experience of receiving daily suggestions, she recalled the app suggesting for her to *"increase [taking] two products, one I'd never heard of"* and on another occasion to phone Community Care as she may need antibiotics, which she felt *"was a bit overreacting to say the least"* and she was *"sensible enough not to react to that and panic"* but the app should provide explanations and *"some kind of index of jargon"*. Once making contact with Community Care, she described how one of the HCPs was *"quite taken back that they'd actually said after one incident I needed antibiotics"*. This experience also resonated with Petros, who described how reporting a small increase in any of his symptoms lead to the app to labelling him as having a 'bad day', which he did not agree with and was not positive to read.

Whereas Chris felt confusion around the action-related question (*'which action did you take yesterday?'*) which asked him if he *"took more nebuliser"* or took *"steroid tablets"* each day, neither of which he owned. He interpreted that the question was suggesting that he *should* have a nebuliser and steroids at home and that he was missing something that is part of his everyday care. He summarised this concern as *"I don't know whether people with COPD have got steroids to take, whether they've been prescribed them ... so no it doesn't apply to me, but whether it applies to other people, I don't know"*. Once I had explained to Chris that the question was not necessarily an indication that he should have these things at home, he noted that *"maybe the question is correct [in being asked], but it's not correct for me"*, and wondered if by not selecting these options (as they did not apply) it would impact his overall day type by suggesting he had not felt the *need* to undertake these actions.

6.4.4.4 Monitoring as a Safety Net

Patient-generated data being shared remotely with HCPs was felt to be a valuable safety net for patients. They felt value in knowing that HCPs could look at their data

and see any patterns such as *"two or three days, or even two or three weeks, that you've been coughing badly"* (Petros) or *"if I was constantly putting in having problems that obviously something would happen to help me sort that out"* (Lia), and that *"they'd give you a ring to say 'are things okay?"'* (Petros) or *"whenever there's a red flag ... somebody would address it"* (Robert).

Though Robert did not require assistance from the HCPs during the study, he envisaged the procedure of addressing declines in health recorded by the app as being similar to when he once took a blood test and *"[the test] went to the hospital for analysis, they say how high it was, they rang up the GP practice, and the doctor rang me, all within four to five hours"*. For Lia and Chris, they believed that having HCPs connected to their data would help them overcome their reluctance to seek help when it is needed. Lia reflected on a previous exacerbation which led to a hospitalisation (before her time on the study), noting that she did not seek help because *"I'm not a complainer ... I don't like making a fuss"*. Yet she acknowledged that *"that situation would have been avoided had I had that [app] then"* as *"whereas I didn't think I was that bad, I was blue lighted into hospital"* and *"someone would come to see me based on the app at that point in time"*.

Likewise, Chris and his wife felt that having a HCP in the loop would help to overcome his strong reluctance of *"disturbing anyone"* about his health problems. In fact, Chris' wife recalled that one strategy she takes to convince Chris to visit the doctors when he is unwell is to *"call the doctor to say Chris is really poorly, will you call him and tell him you want to see him?"* (Chris' wife), so the fact that the app is automatically connected to *"a specialist"* (Chris) who can get in touch could make a positive difference to his management approach. In addition to being a safety net, the app had a day to day benefit of being a *"reassurance tool"* (Robert) whereby *"it was giving me reassurance that what I'm doing is correct"* (Robert) and helped in *"in deciding whether I should go and see the doctor ... [before using the app] the chances are I would have ignored it and suffered"* (Robert) and *"at the end tells you to something ... it tells you if you've been a good boy, or you've been a naughty boy, or whatever the case will be"* (Chris).

6.4.4.5 Uncovering Insights in Reported Data

An important part of the self-monitoring process was the ability to view and reflect on any *"ongoing patterns"* (Lia) within the data that is collected over time. Patients felt that, alongside weekly reports, the collected data would be useful in clinic settings with their HCP for *"analysis purposes and perhaps that would add value to my treatment"* (Robert). This could support HCPs to see *"if they can diagnose that you are doing something wrong"* (Chris) in terms of self-management, and take action such as suggesting *"maybe change the inhaler"*. Chris had changed his inhaler throughout the study, and felt the app data reflected that he felt better. He felt this was particularly important as he is often advised to have his annual COPD review *"in the summer month when you're not on no antibiotics, you're living a normal life"* and visualising his symptoms over time could be beneficial for demonstrating what his symptoms are like across the year, and if *"there's too much in the red, or in the black, or in the green, there should be a methodology of saying 'this is what we've got to do'"* (Chris).

In addition to clinic settings, it was important that patients could obtain insights into their data themselves. Lia and Petros raised the need for *"a sort of picture of a continuum"* (Lia) of their *"personal judgement [of their condition] based on your own experience"* (Robert), with Petros highlighting *"you can only look at it day by day, you're not getting statistics off it"* and there should be *"a chart that says 'in January you had 15 days where you were clear and then 10 days where you were breathless or coughing"*. Aggregated insights about symptoms was thought to *"give you a bit more of an interest to use it [the app]"* (Petros) as it could identify if *"there was pattern as to when as to when things got bad"* (Lia) which would provide longer-term benefit.

6.5 Discussion

The following sections present a discussion on the lived experience of self-monitoring COPD symptoms and sharing this data remotely with HCPs as observed within this

case study. I synthesise the findings from both the patient and HCP experience, creating three core points about: (1) 'safety nets and accountability'; (2) 'trusting data and algorithms'; and (3) 'considering local and individual contexts'.

6.5.1 'Safety Nets' and Accountability

Accountability directly stems from the notion of responsibility, which has been defined by Bivins (2006) as *'a bundle of obligations associated with a job or function'*, including moral and professional obligations. Accountability is *'blaming or crediting someone for an action'*. In healthcare research accountability has been explored in the context of hospital staff addressing inaccuracies in patient records (Murphy and Reddy, 2017), accessing healthcare data and holding HCPs accountable for its use (Gajanayake et al., 2011), accountability for information provided by medical artificial intelligence systems (Academy of Medical Royal Colleges, 2019), and creating transparency around cost and quality of care to patients (Hendee, 2008). This study has extended the notion of accountability in healthcare contexts by showing how it arises when HCPs receive patient-generated data remotely as part of the COPD self-monitoring process.

The findings from this study have demonstrated the value that patients placed in sharing their self-monitoring data with HCPs remotely, which was perceived as a 'safety net' in case of health decline. This is consistent with findings in the telemonitoring space, where COPD patients have reported feeling comforted by being virtually connected to HCPs (Brunton et al., 2015; Dahl et al., 2018; Nadarajah et al., 2019). Yet in this study, the patient perception of the app as a safety net clashed with how the HCPs were willing to engage with the patient-generated data. While the HCPs' overall motivations to support patients to use this app was centred around improving patients' self-management and independence, in reality it created a situation which resembled *supported* self-management. Bardram et al. (2005) described the process of home-based monitoring as a 'collaborative activity system' between the patient and the HCP, which can transform the collaborative work of both actors in the system, having consequences for care practices and divisions of labour. The self-monitoring

process observed within this study also embodies a collaborative activity system, as both patients and HCPs collaborate together in the monitoring process (albeit with contrasting perceptions of how this should be realised). We can use the concept of the collaborative activity system (Bardram et al., 2005; Engestrøm, 1993) as a theoretical lens to understand the effect that this double loop self-monitoring activity had on both the patient and HCP.

Bardram et al. (2005) demonstrated how the introduction of a home-based monitoring system for hypertension transformed responsibilities within the existing collaborative activity system. They noted how the activity of taking blood pressure readings transformed from an activity that is driven by the GP, to one that is driven by the patient (a change in division of labour). In the context of this study, changes to the divisions of labour were also observed as a result of the self-monitoring process. However, there was a notable clash in the perceived desirability of this change. Outside of the study's context, HCPs perceived patients to be responsible for actively informing them about declines in health (i.e. an activity intended to be driven by the patient). However, remotely sharing patient-generated data created an unintended and undesirable shift in the responsibilities of care (a form of labour division[14]). In this instance, HCPs felt responsible, and subsequently accountable, to identify declines in patients' health based on the data. They also felt accountable to actively investigate why a patient has not input their data in situations where there are gaps in data entry. This had a notable impact on assistant practitioners, who began to take on responsibilities which were perceived to be outside the bounds of their role, including care responsibilities (taking phone calls from patients querying medication suggested by the app) and technical activities (helping patients with difficulties using the app). However, as the assistant practitioners were the 'familiar face' that recommended the app and who patients saw during PR classes (where the study was advertised),

[14]This can be thought of as a see-saw effect, when the perceived responsibilities of the patient within the self-monitoring activity decreases, the perceived responsibilities of the HCP increases (and vice-versa).

questions were directed to them.

This concept of shifts in responsibility of care has been explored by Nunes and Fitzpatrick (2015) around how patients and carers collaborate for self-care. They noted that carers may begin to perform a larger share of self-care activities as the patient's condition advances (thus their 'share' of the division of self-care increases). Here, I highlight *unwelcomed* shifts in responsibility of care between the patient and the HCP arising from the introduction of a new mediating technology. This undesirable consequence has been observed in previous research into double loop technologies for monitoring of bipolar disorder (Bardram and Frost, 2018) and telemonitoring in COPD (Brunton et al., 2015; Fairbrother et al., 2013). Though they did not explore or unpack concepts of accountability and shifts in responsibility explicitly, Bardram and Frost's (2018) work reflected on how patients believed monitoring their symptoms was useful, as it was tied to the belief that HCPs would be monitoring the data and acting as a 'life jacket' (pg. 181). In practice, they found that this could not scale to a large number of patients and became challenging for the nurses who were reviewing the data.

Whereas research by Fairbrother et al. (2013) briefly noted how the process of telemonitoring created a situation where COPD patients actively relied on HCPs to be responsible for managing the patient during periods of illness (particularly patients that were severely unwell). In my study, the patients were not deemed to have severe COPD and there were no reports that patients had *actively* deferred responsibility to HCPs (although patients had noted that a benefit of the app would be that HCPs could notice health declines). Instead, HCPs felt that shifts in responsibility were inherent and implied through the nature of receiving patient-generated data remotely. Unlike traditional telemonitoring, there were no pre-established agreements within this study where HCPs would be jointly responsible with the patient for actively detecting exacerbations. This observation highlights how remotely receiving patient-generated data can give rise to accountability concerns that create an undesirable shift in responsibilities of care. Until now this observation had only been explored in the context of telemonitoring for COPD.

Previous work has explored how boundaries can become blurred in HCPs' work due to technology that mediated contact between them and patients (Brunton et al., 2015; Cheng et al., 2015). Cheng et al. (2015) discussed how professional boundaries became blurred during a mobile trial that sought to integrate patient-generated data about preterm infants and their parents into the clinical workflow. They described how clinical support staff had prominent concerns over liability and responsibility related to giving health advice about preterm infants during the trial, as the HCPs were not the primary caregivers for the infants which they received data about. Whereas Brunton et al. (2015) also discussed blurred responsibilities, however, this was in the context of HCPs being required to undertake technical tasks to support COPD telemonitoring. They discussed how studies about COPD telemonitoring showed that there was an increase in HCPs having to undertake technical tasks, such as setting up equipment in the patients' home and investigating equipment failure. These findings about blurring the boundaries of work by Cheng et al. (2015) and Brunton et al. (2015) draws parallels with my study, as assistant practitioners began to take on the roles of the medical and technical 'advisors', helping to clarify app recommendations to patients and resolve technical problems. It is important to acknowledge how undesirable changes to the HCPs' role can arise when supporting remote monitoring contexts. These role changes do not just increase work for HCPs, but also creates tension as the HCP reluctantly becomes responsible for new activities. These changes can impact how willing a HCP is to accept and support particular interventions.

6.5.2 Trusting Data and Algorithms

Previous work has noted a plethora of challenges raised by HCPs about using patient-generated data within, and outside of, clinic settings. For example, challenges relating to how HCPs interpret patient-generated data captured from a multitude of different devices (Abdolkhani et al., 2019; West et al., 2016, 2017) and in different formats (Chung et al., 2015), interpreting the meaning of this data more generally (Kim et al., 2017) especially sporadic entries (West et al., 2018), finding adequate time to re-

view patient-generated data within and outside of clinic (Chen et al., 2014; Schroeder et al., 2017), and tensions around what patients want to track versus what HCPs believe is meaningful to track (Zhu et al., 2016). My research has uncovered how subjectivity in patient-generated data, paired with the perceived opacity of the algorithm[15] used within the app, created trust concerns for HCPs. HCPs felt distrustful of the patient-generated data for two reasons. The first reason was because the daily reports were created using patients' 'subjective' perceptions of each symptom measure. The second reason was because there was a lack of clarity about how the app generated the daily suggestions to give to the patient. It was also observed that some patients began to question the applicability of the questions and daily suggestions, calling for personalisation capabilities.

6.5.2.1 Trusting Subjective Patient-Generated Data

Concerns around the subjectivity of patient-generated data and how this impacts clinical reliability is not a new concept (Bardram and Frost, 2018; Kaptein et al., 2009; Mohan and Sethi, 2014; Troosters et al., 2013). For example, it has been observed that there is a difference between actual activity levels and perceived activity levels in COPD patients (Pitta et al., 2005; Troosters et al., 2013). This demonstrates how relying on patients' perceptions of their behaviour and symptoms may not produce clinically reliable data[16]. Although previous COPD clinical trials have used symptom diaries and scores which rely on patients' own judgement of their symptoms (Casanova et al., 2015; Ghobadi et al., 2012; Leidy et al., 2011, 2014), this data is not specifically

[15] Recall an algorithm was used to categorise the patient's day type according to their data entries and provided suggestions for management.

[16] I do not argue that patients' perceptions of their condition is not important. I argue that perceptions may differ from reality, and depending on the context, this can create challenges for using the patient-generated data for decision-making.

designed for remote monitoring purposes. Where data is captured for remote monitoring of COPD, telemonitoring studies have employed 'objective' measures that aim to mitigate the concern around reliability (Sanchez-Morillo et al., 2015; Tabak et al., 2012; Velardo et al., 2017).

For example, to mitigate variability in patient-generated data, Velardo et al. (2017) used pulse oximeter readings alongside self-assessed breathlessness ratings for remote monitoring of COPD. Whereas Sanchez-Morillo et al. (2015) dealt with variability in patient-generated data by calculating a three day moving average of the latest entries, which is then given a score that is presented to HCPs. In this case study, the HCPs felt strongly that rating breathlessness without any objective measures and additional context could present a potentially misleading account of the patient's condition. The HCPs knew that the experience of breathlessness can be inherently subjective, and can be influenced by factors such as anxiety or fatigue (Bailey, 2004; Carel, 2018; Heinzer et al., 2003; Maurer et al., 2008; Xu et al., 2008). Previous work has also noted that the similarity between COPD symptoms and features of panic attacks can make it challenging for patients themselves to properly identify the reasoning for altered bodily functions such as breathlessness (Dowson et al., 2004a). This in itself is not the core problem as the COPD team are used to helping patients manage their breathlessness regardless of how it arises. However, in remote monitoring settings when the patient is absent, navigating ambiguity in the data can be challenging (Andersen et al., 2011). This can be contrasted with clinic settings where the patient and HCP can collaboratively interpret the patient-generated data (Mentis et al., 2017). As the app relied solely on subjective assessments of symptoms, there were concerns that the HCPs and patients may overreact to the data when the app labels the patient as having a 'bad day' or 'flare up'. Overreacting in this context refers to perceiving a patient to be more unwell than they clinically are, and subsequently acting on this perception.

Previous studies in telemonitoring contexts have shown that COPD patients have consciously opted to under-report their symptoms to avoid 'burdening' HCPs (Dahl et al., 2018). Patients also noted under-reporting their symptoms in situations where

they were unsure how their current symptoms compared with their usual baselines (Dahl et al., 2018; Nadarajah et al., 2019). This can lead to *underreacting*, in other words, perceiving a patient to be in better health than they clinically are. As patients may not have medical backgrounds, they can be led to a false sense of security if the app provides incorrect information based on them under-reporting. Underreacting can also occur in situations when algorithms mistakenly provide incorrect information to the patient (i.e. not as a result of the patient under-reporting their health) (Becker et al., 2014; Wolf et al., 2013). As shown, underreacting can occur as a result of the way a patient reports their data or as a flaw in the algorithm. However, my study has highlighted the concept of unintentional *overreacting* due to subjectivity in patient-generated data, and the subsequent impact this can have on patients and HCPs.

In my study, due to the uncertainty around the reported symptoms which are remotely shared, the HCP would have to make contact with the patient for clarification. This has implications for what Bardram and Frost (2018) described as 'social scalability', a feasibility dimension of technology deployment that must be considered alongside technical scalability. When Bardram and Frost (2018) introduced this term, they were discussing the challenges that nurses faced when reviewing remotely received patient-generated data about bipolar disorder. They discussed the ways in which nurses were uncertain about how they should act on the data, as how patients rate their mood can vary considerably. They observed how nurses felt they needed to know each patient's context to support data interpretation, which has significant challenges for social scalability. This demonstrates how the type of data that is collected and its context is a crucial step to supporting social scalability of remote monitoring contexts. Though these factors are also important for interpreting patient-generated data in clinic settings (West et al., 2016), the absence of the patient in remote monitoring contexts magnifies this challenge.

6.5.2.2 Trusting Opaque Algorithms

In addition to the challenges of subjective patient-generated data, understanding how the app's algorithm functioned was another concern highlighted by HCPs. The HCPs questioned various elements of the algorithm, including: who designed the algorithm (did they have a specialism in COPD?), how the algorithm made decisions on what to suggest to the patient (how did it convert the patients' responses into daily suggestions?), and how up to date this information was (was it based on the latest clinical guidance?) The uncertainty around this made HCPs distrust the app's daily suggestions, particularly when the app suggested that a patient may need antibiotics, something which both the patient and HCPs did not agree with (section 6.4.3.3, pg. 229). Hartswood et al. (2003b) and Yang et al. (2019) both discussed how users' perceptions of the reliability of evidence that is generated by decision support technology affects their trust and acceptance for its use in practice. In Hartswood et al.'s (2003b) work on computer assisted mammogram readings, they argued the importance of mammogram readers being aware of how the algorithm works. This would help readers understand why the technology makes the suggestions that it does, so that readers can better understand how to rationalise its outputs.

Whereas, research by Yang et al. (2019) demonstrated that HCPs require an understanding of how algorithms used within decision support tools have been clinically validated and how they technically work. This was perceived as central to accepting these tools in practice. Both studies by Hartswood et al. (2003b) and Yang et al. (2019) highlight the importance of transparency about algorithms used as part of healthcare technologies. This case study contributes to this understanding by demonstrating how trust concerns arise when the algorithms used within health monitoring technologies are perceived to be opaque. Indeed, these concerns could also arise when HCPs make decisions about what technologies to recommend to patients for self-managing their condition (i.e. even with single loop technology when the HCP is not part of the monitoring process). This contribution, taken together with the studies by Hartswood et al. (2003b) and Yang et al. (2019), uncover key requirements for researchers to sup-

port the reduction of these trust concerns. In turn, this could support building more trustworthy technologies for healthcare. Below I discuss two opportunities to support HCPs to build trust and familiarity with double loop technologies for healthcare.

First, it is important to ensure that HCPs are confident about how algorithms used in healthcare technologies function before the start of the study or real-world deployment. This can be achieved through involving HCPs in the algorithm design. For example, through employing participatory approaches to algorithm design, such as human-centred algorithm design (Baumer, 2017). In this approach, HCPs would be actively involved in designing the algorithm and deciding how it should perform. HCPs can incorporate their expertise on the latest clinical guidance and, if necessary, tailor the outputs towards their local practice guidelines[17]. Patients could also be involved in later stages of this approach to assess how they understand advice produced by the technology. Explainable artificial intelligence[18] techniques should be employed to avoid the 'black box' effect (Holzinger et al., 2017; Rai, 2020; Wang et al., 2019), so that future users independent from the design process can understand the algorithm's decisions and outputs. For example, providing transparency about the medical guidance being used to drive suggestions and how up to date this information is. It is also important to be transparent about how combinations of symptoms are categorised and map to management recommendations.

Second, it is important to provide HCPs with the opportunity to understand how the algorithm works under certain conditions, with the ability to make amendments during the development phase. This can be achieved through the team of HCPs using the technology themselves for a short period of time before the study officially begins (as a type of autoethnography). During this time they could input data imitating a

[17]Note that this could introduce scalability challenges, but the importance of understanding the local context of clinical work and how this is relevant to design is discussed in the following section (6.5.3).

[18]Explainable artificial intelligence refers to methods that promote visibility about how artificial intelligence systems make decisions and execute their actions (Rai, 2020).

'patient user' and subsequently view this data as the 'HCP user'. Following this activity, a debriefing session could be conducted with the researchers to discuss and unpack any potential findings, with opportunities for amendments to the technology. This supports building an understanding of not just what the algorithm technically 'does' step by step, but how this is realised in practice. Autoethnography has been used in previous HCI studies to develop empathy for the user experience of engaging with a variety of technologies (Bergman, 2000; O'Kane et al., 2014). However, in this context I describe using autoethnography as a strategy to develop a deeper understanding about how double looped technologies perform under empirical use.

Both strategies discussed above can support the better inclusion of end users within the design of double loop technologies. This can in turn support end users to develop stronger trust in these technologies.

6.5.3 Considering Local and Individual Contexts

Similar to how we think about generalisability of scientific work, building generalisable healthcare technology allows solutions to specific problems to transfer across a variety of contexts which encounter similar challenges (Briand et al., 2017). The Community Care service within this case study will not be the only healthcare service that are interested in how technology can support the COPD self-management process. However, the Community Care service has local practices and protocols that have been shaped over time, which are specific to their organisation. For example, how they organise their caseload, how (and if) rescue packs are prescribed, and how they coach patients to better understand their own symptoms. Understanding the individual and 'particular' features of different users and contexts is important for designing for real-world contexts. Bertelsen et al. (2018) argued that by making generalisable solutions the goal of research, researchers risk losing sight of important design questions that

occur in the real world[19]. This case study has highlighted the importance of appreciating the particular features of the Community Care service and COPD patients, which has implications for the design of digital health technologies that aim to support this space.

Hartswood et al. (2000, 2003b) argued that as technology becomes interwoven with everyday work, the design challenge becomes less about *creating* tools and more about how tools can integrate with existing and localised work practices. In this case study, localisation and personalisation of technology was highlighted as an important requirement by HCPs and patients. One concern that HCPs raised about the daily recommendations provided by the app was their standardised nature, which contrasted with Community Care's individualised and localised approach to patient care. Individualising patient care is an important approach to better consider how unique and contextual factors about a patient are relevant to how they are cared for (Weiner, 2004). This contrast was evident when the advice from the app was felt to have conflicted with what the HCPs had advised the patient in the past (such as increasing inhaler usage and suggestions around antibiotics). As a result, the HCPs became distrustful of the app and its recommendations.

Storni (2011) explored the notion of conflicting health information during their study about diabetes self-care. Storni noted that the variety of people involved in a patient's life (such as family, friends, support group members, online mentors, etc) may offer suggestions and advice about a patient's condition. The challenge for the patient is that information from different sources does not always align and can cause the patient to feel conflicted. While Storni (2011) raised an important point about how people can be sources of conflicting health information, this case study highlights how self-management technology can be the source of this conflict. This is particularly challenging when technology is being designed to support the

[19]Note that Bertelsen et al. (2018) do not suggest research on the particular is mutually exclusive with generalisability.

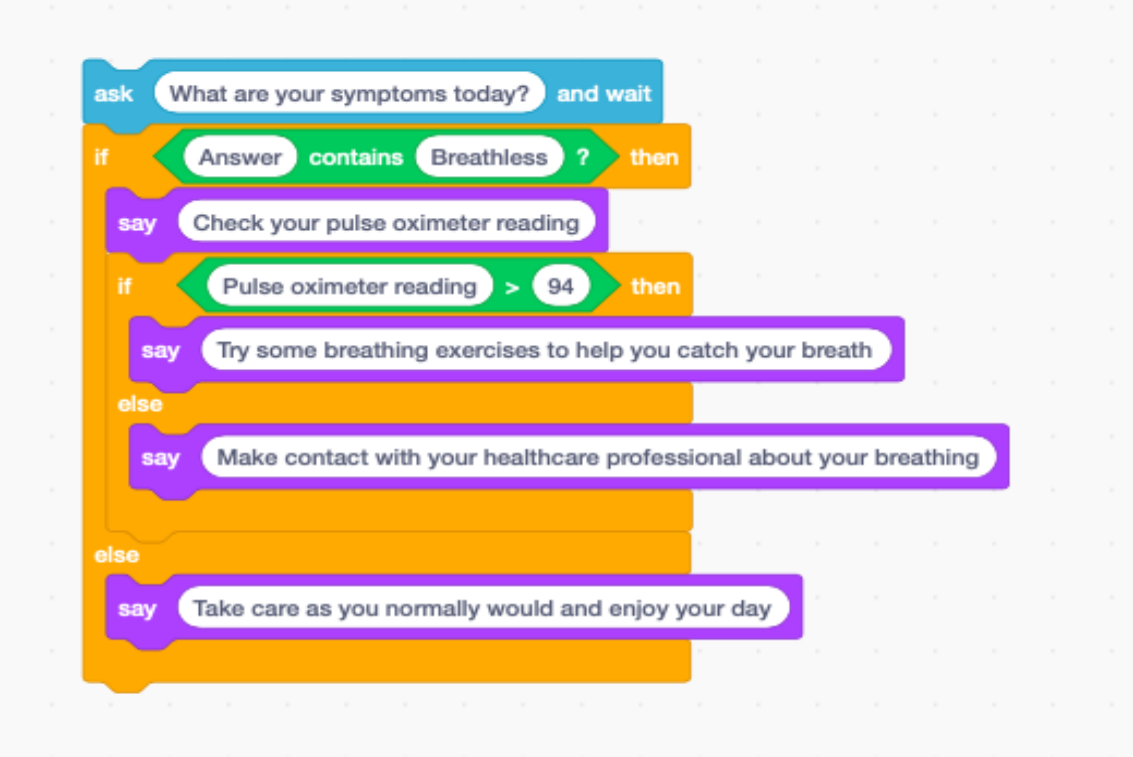
self-management journey, as these technologies should be perceived as reliable and safe sources of support and information. If self-management technologies provide health information that conflicts with advice from HCPs, this could cause patients to make decisions or hold beliefs about their condition which are inaccurate and possibly harmful. It is important to note that there were no instances of patients being exposed to harm in this study. However, the concerns about technology providing information that conflicts with the advice of HCPs makes this an important point to raise.

Patients raised a need for more personalised solutions to self-monitoring that applied to their individual context. They expressed that a more tailored and adaptive approach that can learn about users could better support effective self-management. In fact, a lack of personalisation can render the app useless for some patients due to the lack of individual applicability. This was observed with one participant who noted that the app's suggestions were not always helpful for the patient: *"it's no good saying with him sit down, because that's what he's doing most of the time anyway"* (Chris' wife, section 6.4.4.2, pg. 234). Whereas there were also instances where patients felt the questions were not relevant to their situation, or that the suggestions from the app did not align with how they preferred to manage their condition (recall that some patients raised concerns about using antibiotics as a first resort, see section 6.4.2.2, pg. 224). Without some level of personalisation, the app can only produce suggestions based on hard coded *assumptions* about the patient's capabilities, needs, or circumstances. As experienced, these assumptions can be incorrect and subsequently influence the perceived usefulness of the technology.

Axelrod et al. (2009) emphasised the importance of considering the real lives of people living with a certain condition when designing technology to support them. Their study focused on assistive technologies to support people who have had stroke. They highlighted the importance of dismantling the utopian vision of how users will engage with assistive technologies for stroke, by taking into account the lived reality of people who have suffered from stroke. They discussed the importance of personalising approaches to assistance that take into account the person's physical needs and motivations to best embed support into their lifestyle. Similarly, Storni (2011) dis-

cussed the challenges of designing universal solutions to diabetes self-management, as these solutions do not consider the individual circumstances and lives of each patient. In response to this challenge, Storni (2011, 2014) created a system to support diabetes journalling which allows patients to personalise the data they track. The system involves patients creating 'tags' to track data about their different self-management practices. The findings from both Storni (2011) and Axelrod et al. (2009), paired with the findings from my case study, present a strong case for self-management technologies to better support personalisation. I discuss two opportunities for self-management technologies to support personalisation for patients with COPD below.

The first opportunity for self-management technology to support personalisation is through providing customisation. Technology that allows individual patients and their HCP to collaboratively customise and tailor the technology to the individual patient's needs and circumstance may be promising. A similar approach was used in previous research around personalisation of self-management technology for autism (Simm et al., 2016). In their work, adults with autism were able to physically and functionally customise wearable technology bracelets that collected data about anxiety to support self-management and reflection. The technology was built with the intention for it to be customised at the user's end to support individual needs. This approach could help to mitigate patients' concerns that there is a *"one message applies to all"* approach to support (Robert, section 6.4.4.2, pg. 233). In addition to supporting customisation for individual patients, customisation capabilities could also be offered to HCPs to support localisation. For example, HCPs could be offered the opportunity to tailor the information provided by the app to align with their local healthcare practice. One way this could be achieved is through block based programming approaches, which allows users to customise the functionality or outputs of the app (see an example in Figure 6.4). Block based programming approaches have been used in previous work to teach people how to program, making it an effective way for technology non-experts to tailor the functionality of technology (Dasgupta and Resnick, 2014; Maloney et al., 2010; Weintrop and Wilensky, 2015).



In this example the HCP can customise the messages and thresholds for the patient. This image was created using Scratch (https://scratch.mit.edu).

Figure 6.4: An conceptual example of using block based programming to customise the functionality of self-management technologies to support localisation and individualisation.

The second opportunity for self-management technology to support personalisation is by learning about the patient over time. Artificial intelligence techniques, for example, could support building a stronger and more individualised understanding of the patient's capabilities and limitations. This would ensure that the technology provides individualised support to patients and does not suggest actions that are beyond the bounds of what can be achieved. For example, patients could specify their condition stage or capabilities (which should be modifiable as the condition changes over time), and this information should influence the management suggestions that are provided by the technology. It is important to note that as technology supports COPD

patients in self-managing their condition, the way that potential declines in health are visualised by the technology must be communicated sensitively (Lupton, 2013; McNaney et al., 2015). As we envisage technology that could adapt to patient's needs and capabilities, it is likely that declines in health may be reflected by the technology, as COPD is a progressive condition.

Both opportunities described above can help to support building and customising double loop technologies for COPD care. However, these opportunities could extend to other digital health technologies that support patient monitoring and offer self-management advice. Through offering stronger personalisation for patients and localisation for healthcare services, these technologies can improve the value they offer for COPD care. This could also contribute to the sustained use of these technologies in practice.

6.6 Study Limitations and Reflections

An important limitation about this study relates to the extend to which the findings can be generalised. There was a total of eight[20] participants (four HCPs and four patients) with a total of 18 data items (1 focus group, 12 interviews, 4 phone call discussions, 1 set of summarised app engagement statistics on each patient). Though the sample size is small, my intention is not to argue that the findings will apply to every instance of patients sharing data remotely with HCPs. Instead the study has taken an exploratory approach to document the real-world lived experiences of using an mHealth app to self-monitor and share data about COPD symptoms. Through doing so I have been able to devise rich conceptual and empirical findings that can inform future work in this space.

[20]There were nine participants if participant Chris' wife is included as a participant. However, she was not involved in the same way as the other eight participants.

Moreover, Crabtree et al. (2013) have argued that the underlying social arrangements of interaction can serve as a basis of generalisability across a cohort – even in single cases. The collaborative monitoring process in this study can be considered as a form of social arrangement between patients and HCPs. Through situating my findings within previous literature on self-monitoring, I have built a case that prepares my insights for potential transferability across cases of similar research (Yin, 1994). The in-the-wild approach for this study adds to the study's ecological validity, enhancing their reliability (Flyvbjerg, 2006). Therefore, I argue this research provides valuable insights despite the sample size being small.

A second important limitation is the self-selection bias with patient recruitment. Recruitment was a significant challenge for this chapter. The patients who participated had an interest in exploring how technology could support their self-management. Moreover, they were recruited from the PR programme. It has been shown that lack of motivation, lack of confidence, and perceived limited benefit of PR are among some of reasons why patients drop out of PR — or decline the intervention altogether (Fischer et al., 2009, 2007; Keating et al., 2011). Therefore, by recruiting from PR, I was already selecting from a patient sample that were motivated and engaged with the Community Care service. This means I do not capture the perspectives and experiences of those who may be less confident or motivated to self-manage their condition using technology. This should be taken into account when interpreting the study results.

Finally, I wish to reflect on a practical ethical challenge relating to returning loaned smartphones at the end of the study. Participant Chris was loaned a smartphone for the study and reported enjoying the process of self-monitoring, feeling that it was positive to his self-management. As per the study protocol which Chris consented to, he was required to return the smartphone at the end of the study. This meant he could not continue using the app after the study (unlike the other patient participants who had their own smartphones). As part of their focus on practical ethical concerns that arise with research in-the-wild, Race et al. (2020) and Taylor et al. (2013) discussed the challenges associated with taking equipment away from

communities that have participated in research. Taylor et al. (2013) highlighted the importance of expectation management and making it clear at the beginning of the study if the participant will be able to keep the study equipment.

I had made Chris aware both verbally and in writing before he consented to the study that the smartphone would need to be returned after the study — and he understood this. Chris had no problems returning the smartphone to me but expressed feelings of disappointment about no longer being able to participate in a process he found valuable. Likewise, I felt as though I was taking away a valuable self-care practice from him. Though it is not always possible for participants to keep study equipment, researchers should consider gifting the study equipment to participants (where safe and possible) to avoid any disappointment around the conclusion of the study. If it is not possible, other ways to provide value back to the participant should be considered. For example, providing them with hard copies of visualisations of their health data that they can use after the study[21].

6.7 Chapter Summary

This chapter explored the lived experiences of self-monitoring COPD symptoms and sharing this data with HCPs. I examined the experiences of four patients who self-monitored their symptoms using an mHealth app for 30 days, and four HCPs who were sent the symptom data. First, I conducted a focus group with two senior HCPs to understand their motivations for introducing a self-monitoring app onto their service. Then, four patients were recruited onto the study and participated in interviews. The interviews scoped their motivations for using a mHealth app to self-monitor their symptoms and share this data with HCPs. After this interview, the patients began self-monitoring their symptoms. Approximately two weeks into the process, I phoned

[21] I was unable to do this, as I did not have access to patients' personal health data from the app.

patients to check in on their experiences. After 30 days of self-monitoring, I conducted final interviews with patients to understand their experiences on the study. After each patient completed the study, I conducted interviews with all four HCPs to understand their experiences of receiving patient-generated data on the study.

The findings uncovered the challenges and opportunities involved when using self-monitoring technologies for COPD and sharing symptom data remotely. This included: highlighting tensions around safety nets and accountability (where patients and HCPs had conflicting perceptions about sharing symptom data remotely as part of COPD care); HCPs' concerns about using COPD symptom data that is perceived as too 'subjective'; the requirement for digital health technologies to offer greater transparency and explainability about how their algorithms work; the need for self-monitoring technologies to localise their management suggestions to the healthcare services which support its use (otherwise conflicting advice may be given to the patient); and the importance of self-monitoring technologies offering personalised approaches to self-management that support individual patients' needs and contexts.

The next chapter presents an overall discussion on the findings from each research chapter (4, 5, and 6). It synthesises the research findings to draw out the main contributions of this thesis about the role of data supported decision-making technology for respiratory care.

Chapter 7

Discussion

The previous three chapters explored the role of data supported decision-making (DSDM) technology for respiratory care with healthcare professionals (HCPs) and people with Chronic Obstructive Pulmonary Disease (COPD). This chapter provides an overall discussion on my contributions to knowledge, drawing on the findings from each research chapter. First, I review the original aims of this thesis and outline how I explored them. Then I present a discussion about my key contributions across all research chapters, comparing and contrasting them with pertinent related work. Finally, I conclude this chapter by providing a brief summary of how my overarching contributions can be positioned within the current state of knowledge in this space.

7.1 Review of Research Aims

The role of DSDM technology in healthcare is an increasing area of interest in medical and computer science research, particularly as we enter an age of advanced technologies, big data collection, and a growing global population with various health needs. This thesis was driven by the need to explore how DSDM technologies could support

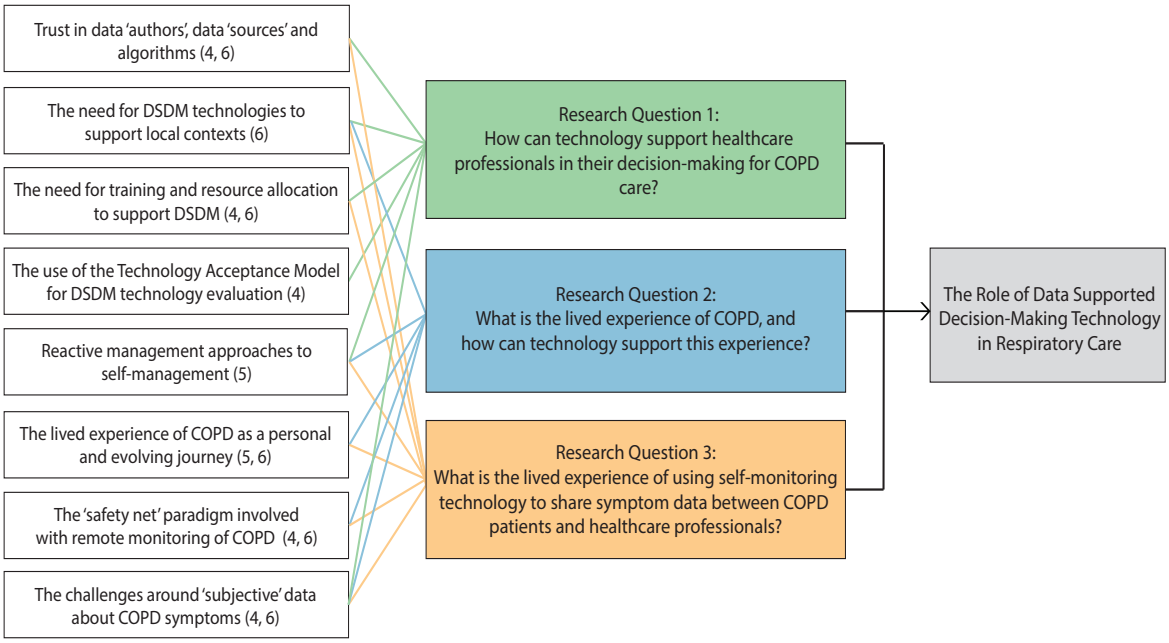
the care for people with COPD. It was important to explore this from the key perspectives of people with COPD (who live with the condition each day) and respiratory HCPs (who provide ongoing care for people with COPD). Including both perspectives builds a strong understanding about the possibilities for DSDM technologies to support chronic respiratory care — both now and in future. To do this, I went beyond simply involving people as 'users' in requirements gathering phases of research about DSDM technologies. Instead my thesis aimed to include a deep consideration of people's needs and contexts at each stage, while exploring how DSDM technologies could support their everyday lives and work.

My thesis aimed to answer three research questions about the role of DSDM technology in chronic respiratory care: (1) how can technology support healthcare professionals in their decision-making for COPD care? (2) what is the lived experience of COPD, and how can technology support this experience? and (3) what is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals? I explored these research questions by first identifying gaps in the current literature relating to technologies for DSDM and COPD self-management (Chapter 2). Then I carefully crafted a mixed methods research methodology and reflected on the ethical and methodological challenges in this space (Chapter 3). Finally, I conducted three novel pieces of research to answer my research questions (Chapter 4, 5, and 6). I discuss and summarise my contributions to knowledge arising from this thesis in the sections below. These contributions are relevant to the fields of Human-Computer Interaction (HCI) and Health Informatics. However, some contributions may also have relevance to other healthcare research communities and the practices of healthcare staff.

7.2 Discussion of Research Contributions

This section provides a discussion on the main research contributions from this thesis. I situate these contributions among key literature to demonstrate how my research

adds to the body of knowledge on DSDM technologies for chronic respiratory care. Figure 7.1 depicts a visual representation of how each research contribution (arising from the research chapters) maps to each research question, ultimately informing our understanding about the role of DSDM technology in respiratory care. These contributions are discussed in detail in the following sections.



Note: the numbers in brackets indicate which research chapter the finding has emerged from.

Figure 7.1: How each research chapter contributes to each research question.

Trustworthiness of data and algorithms plays a central role in how DSDM technologies can support HCPs in their decision-making.

'Trust' and its impacts on decision-making was a prevailing theme across both Chapter 4 (Data Supported Decision-Making) and Chapter 6 (Self-Monitoring and Collaboration). I have shown that data and algorithms used as part of DSDM technologies

must be perceived as trustworthy for their use in the decision-making process. As discussed by Hartswood et al. (2003b) and Jirotka et al. (2005), trust and transparency in healthcare technology is important for a user to make sense of its contributions and understand how it should inform decision-making. In this thesis, I expanded on this understanding about the importance of trust and transparency by uncovering how it influences decision-making about COPD care. In Chapters 4 and 6, I demonstrated why data that is used to facilitate DSDM technologies should not be left opaque to users (and concerns that emerged when it was). More specifically, I have contributed new understandings about the ways that lack of trust in *data authors* (Chapter 4 and 6), *data sources* (Chapter 4 and 6), and *algorithm transparency and explainability* (Chapter 6) can present significant challenges for how willing HCPs are to engage with DSDM technologies.

Who the data authors[1] were had significance for how the data was perceived, as HCPs needed to factor in any potential variability within the data to judge its reliability. Though Cicourel (1990) first discussed the ways that information reliability was influenced by professional hierarchy in healthcare contexts, I have unearthed for the first time how differing areas of clinical specialism also impacts perceived reliability. I took this concept further to understand how it influences how users engage with DSDM technologies. For example HCPs discussed that they would engage more with spirometry data depending on its author: *"I definitely believe what came from the Hospital over the GPs [general practitioners]"* (Chapter 4, section 4.4.6.5, pg. 129). This trust issue became particularly pertinent when collating data from different HCPs and healthcare organisations, which lessened HCPs' confidence in its reliability. It is important to acknowledge that this challenge cannot be resolved by technology alone. These trust concerns stem from challenges relating to spirometry training and lack of consistent understanding about COPD. However, these concerns do have implications

[1] Recall that data authors are anybody that records the data being used for decision-making (in this research it was patients and HCPs). This concept was introduced in Chapter 4 (section 4.5.1, pg. 130 onwards).

for how data is visualised and presented for decision-making. When collating data from multiple different HCPs, providing clarity about who[2] has recorded the data is an important feature for visualisation. In future, as concerns about spirometry training are addressed, digital badges could be used alongside the data to indicate which organisations have completed adequate training (Anderson et al., 2013). This is one way that digital techniques could be used to support the trust building process about data from specific authors (both considering their clinical specialisms *and* their professional roles (Cicourel, 1990)).

Data sources[3] used across the organisations in Chapter 4 had flaws well known to HCPs. This meant that *transparency* about the data sources used within DSDM technologies was important, so HCPs could account for these flaws during decision-making. Repurposing existing data sources for use in DSDM technologies can have implications for data interpretation, as some healthcare data can be perceived as bound to the context of its production (meaning it cannot be effectively interpreted outside of the original context it was produced) (Berg, 1999). Whereas I have shown that when repurposing existing data for DSDM support, failure to specify the original source can hinder the data interpretation process. The HCPs needed to factor in known uncertainties about data sources when considering its use and potential weight in the decision-making process. For example the Hospital marker system required manual flagging of COPD patients, so its use to determine the number of COPD patients in hospital is unreliable as it is not a *"true list ... there will be patients that probably slip through the net"* (Chapter 4, participant C7, section 4.4.6.1, pg. 116). While data sources that lack complete accuracy are unideal, HCPs could use

[2]That is, clarifying their role, not naming the specific individual, as this would be considered too *"political"* (Chapter 4, participant BI2, section 4.4.2.2, pg. 100).

[3]Recall that data sources refer to databases or systems in which data is pulled from for the purposes of collation and visualisation on DSDM technology. For example, the Hospital marker system from Chapter 4 is an example of a data source (Chapter 4, section 4.4.2.3, pg. 100).

their local understanding of the data sources and professional vision to interpret its utility (Goodwin, 1994). One way to promote transparency about data sources used in DSDM technologies is by clearly visualising to the user where the data originates from. Taking this a step further, visualising uncertainties[4] in the data can help to inform its reliability. Future work should carefully consider the potential effects of using particular data sources for DSDM support in clinical settings.

The concept of algorithm transparency and explainability was highlighted in Chapter 6, when HCPs raised trust concerns about the outputs of the 'How Are You Today' app used within the case study. There was a strong need to understand how the algorithm worked to understand its potential contributions to decision-making and management of patient care. As highlighted in the previous two paragraphs, *who* designed the algorithm and *what data* it was based on was important criteria for explainability. For example, whether the algorithm designer was a respiratory specialist and whether the algorithm reflected the latest clinical guidance was important. This knowledge helps the HCP to judge the suitability and validity of the outputs for decision-making. It also gives HCPs the confidence to recommend the app to their patients, knowing that they can trust and justify the outputs.

Explainability can help facilitate the trust building process between HCPs and DSDM technology, providing them with key knowledge required for its initial acceptance. Jirotka et al. (2005) noted that workers establish trust with technology in similar ways as they establish trust with human colleagues: by understanding its respective strengths and weaknesses. Algorithm explainability is recognised for its importance for healthcare technologies (Adadi and Berrada, 2020; Ahmad et al., 2018; Bussone et al., 2015; Holzinger et al., 2017). One way to design DSDM technologies that promote explainability is to incorporate participatory algorithm design activities when designing the technology (Baumer, 2017). This could include involvement of medi-

[4]For example, uncertainties about the completeness or quality of the data. If data is pulled from the coding department in the hospital for example, it should be communicated that this data is provisional.

cal experts during algorithm design, providing them with the opportunity to decide where and how explainability should be communicated. For example, Chapter 6 uncovered the need to include information about the designers of the app's algorithm and information about what clinical guidance the data is based on. Additionally, when designing technologies which are both HCP and patient facing, like in Chapter 6, including patients when testing the algorithm's outputs can provide confidence that the outputs are understood by patients as intended. It is also important to understand how algorithms 'behave' beyond their written step by step instructions. To explore this, HCPs could take an autoethnographic approach to trial the technology so they can assess its behaviour under empirical use[5] (Bergman, 2000; O'Kane et al., 2014).

There is a wider acknowledgement about the importance of providing trustworthy technologies for healthcare services (and patients). Hence organisations are seeking to provide platforms that can showcase a library of reviewed and accredited health apps (NHS Digital, 2018; ORCHA, 2018). It is important that these platforms carefully consider how explainability and transparency has been offered and assessed, considering the points described above, as part of their judgement criteria. This will become particularly relevant as healthcare technologies grow to be more complex and sophisticated in nature.

To support existing work and care practices, DSDM technologies must provide support that is applicable to the local healthcare context.

Both Chapter 4 (Data Supported Decision-Making) and Chapter 6 (Self-Monitoring and Collaboration) highlighted the need for DSDM technologies which conformed to, and integrated with, local ways of working and providing care. The co-design

[5] I discussed this approach in Chapter 6 as being specifically useful for double loop technologies, so that HCPs could understand how the 'patient' input influences the outputs that are shown to them and the patient (Chapter 6, section 6.5.2.2, pg. 247).

process in Chapter 4 accounted for the various local arrangements of both the Hospital and Community Care, to create support that would align with their collaborative needs. Whereas in Chapter 6, integrating a standardised symptom monitoring app into clinical practice clashed with Community Care's requirement for localisation. Though healthcare organisations will follow evidence based best practices[6], how they carry out their work will be influenced by their local preferences, demands, and regional guidelines. For example, HCPs from different organisations may have different medication prescribing habits (Davies et al., 2014; Hemminki, 1975; Robinson, 2018). Likewise, the local arrangements that healthcare services have with one another will influence how work is organised (as seen in Chapter 4 and Hartswood et al. (2003a)). This is not to say that DSDM technologies cannot be designed for more than one context at a time. Rather, this point emphasises that local differences can impact how DSDM technologies are (dis)used and (un)valued (Berg, 1999; Hartswood et al., 2003b).

Chapter 6 showed how HCPs felt the management suggestions provided to patients by the standardised app misaligned with the advice given from their local healthcare service (Chapter 6, section 6.4.3.3, pg. 228). As a result, HCPs on one occasion had to 'correct' the advice provided by the app, which created broader concerns about accountability and increasing their workload (Chapter 6, section 6.4.3.2, pg. 228). This highlights the importance of considering local needs and ways of working when designing DSDM technologies to support patient care. This is particularly relevant for technologies which may be recommended to patients by healthcare services to support self-management of their condition. In addition to following clinical guidelines when providing advice to patients, HCPs may wish to personalise management advice based on individual patient needs (Savard, 2013; Weiner, 2004). This was summarised in Chapter 6: *"there's [national] guidelines but that will be imple-*

[6]For example, in the United Kingdom, the National Health Service (NHS) will follow guidance set out by the National Institute for Health and Care Excellence. See https://www.nice.org.uk/about (Accessed May 5th, 2020).

mented individually to the patient" (section 6.4.3.3, pg. 228). If guidelines given from the healthcare service and the technology conflict, this can create difficulty for the patient's self-management – and potentially cause harm. This is particularly important given that the lived experience of COPD reported in Chapter 5 (Technology and the Lived Experience) already details the perceived lack of adequate information about self-management and self-care (Chapter 5, section 5.4.1.1 and 5.5.1, pg. 170 and 182). Therefore, this contribution highlights how *localisation* and *personalisation* are important capabilities for technologies which support patients and HCPs.

To ensure that standardised support provided by DSDM technologies does not create discordance with local contexts, front-end customisation capabilities could be offered to healthcare organisations. I discussed in Chapter 6 (section 6.5.3, pg. 250) that customisation capabilities could be provided based on block based programming approaches (Dasgupta and Resnick, 2014; Maloney et al., 2010; Weintrop and Wilensky, 2015). This could allow users to engage with a simple graphical user interface to tailor functionality of the system (see a conceptual example in Figure 6.4, pg. 251). Customising digital health technologies in this way has been explored by Simm et al. (2016) in the context of managing anxiety in adults with high functioning autism. My research demonstrates how customisation should enable localised support on patient and service levels. However how customisation capabilities that support localisation may be offered to HCPs, and realised in practice, requires further investigation.

Integrating DSDM technologies into healthcare practice requires training and resources for HCPs to make effective use of them.

Supporting decision-making extends beyond the process of designing, developing, and deploying a particular DSDM technology into clinical practice. There is a need for the wider sociotechnical system within the organisation to accommodate the role of the technology and the decisions that can be informed by it. Moreover to effectively evaluate and measure the outcomes of introducing a DSDM technology in clinical practice, it must be introduced in an environment that appropriately supports its

intended benefits. My research in Chapter 4 (Data Supported Decision-Making) and Chapter 6 (Self-Monitoring and Collaboration) showed that for DSDM technologies to support HCPs, there is *a need for appropriate* (*cross-*)*organisational protocols and policies* to accommodate and resource ways for staff to respond to the data. This particularly applies to scenarios where the DSDM technology introduces HCPs to data that has been previously unavailable to them in practice.

For example, current organisational protocols may not include activities such as responding to patient-generated data (e.g. patients' symptoms sent remotely to HCPs explored in Chapter 6) and types of service level data (e.g. data about COPD hospital admission rates explored in Chapter 4). This type of data, which was explored in Chapters 4 and 6, was seen to have a more important purpose than simply being 'informative'. The HCPs believed that this type of data should be *acted upon* where appropriate, such as when data shows a patient is struggling with their health (*"you've got to do something with this data"* – Chapter 4, participant C6, section 4.4.6.3, pg. 123) or COPD hospital admissions rates are suddenly increasing (*"[we need] agreements with other Trusts about how we respond to these spikes in admissions"* – Chapter 4, participant H3, section 4.4.2.1, pg. 98). To that end, healthcare organisations must consider and accommodate the decisions that users can (and should) make based on the technology's insights. If the protocols around the use of the DSDM technology are not clearly communicated, HCPs may disengage with the technology over concerns about liability or futility arising from its use (Bardram and Frost, 2018; Cai et al., 2019). This is an example of the ways in which DSDM technologies can influence how healthcare work is carried out, an area which Dowding et al. (2015) noted required further understanding.

However, before considering how these technologies may be used in practice, it is crucial to *consider how HCPs can be appropriately trained to use DSDM technologies*. Chapter 4 revealed that conventional information technology (IT) systems used in practice were often navigated on intuition alone due to time pressures and perceived lack of need for training (section 4.4.2.1, pg. 97). However DSDM technologies may require HCPs to correctly interpret and analyse data that they are *"not used to*

seeing" (Chapter 4, participant C8, section 4.4.6.2, pg. 117). Therefore a lack of training could result in HCPs making incorrect assumptions about, and based on, the data. A lack of understanding about how to safely use DSDM systems can be a key barrier to their adoption (Sarcevic et al., 2012). To an extent the challenges relating to training on clinical systems can be alleviated through intuitive system design. Yet as DSDM technologies become more sophisticated in their data visualisation and capabilities, HCPs may require more formalised methods of training to effectively learn about the system. However as the healthcare domain continues to benefit from new technologies, data analysis skills may become increasingly important for the HCP workforce (Steen and Mao, 2016).

To minimise the time burden required for user training, careful consideration of how the data is presented and articulated on DSDM technologies is crucial. In Chapter 4, I suggested offering alternative views of data to support different levels of data literacy among HCPs (section 4.5.2.2, pg. 144). Different professional roles and expertise must be considered when designing data visualisation, to account for the potentially different levels of analysis and data comprehension skills among healthcare staff (Dowding et al., 2017; Gaissmaier et al., 2012; Islam et al., 2016). Understanding the most effective way to engage HCPs in training on DSDM technologies remains an important topic for future work. For example, considering how flexible and scenario-based training could be feasibly designed to support the safe and effective use of DSDM technologies in practice.

Carefully considering the use of the Technology Acceptance Model in healthcare to evaluate DSDM technologies.

In Chapter 4 (Data Supported Decision-Making), I used a scenario-based evaluation approach and a technology acceptance model (TAM) questionnaire[7] to evaluate the

[7]Recall that TAM intends to predict if a user will accept a new technology (Davis et al., 1989).

DSDM prototype (section 4.3.6, pg. 90). I reflected on how the scenario-based evaluation provided a resourceful way to capture rich qualitative data about factors that can influence the (dis)use of a DSDM technology. These insights can complement the traditional quantitative data captured by randomised control trials, which seek to evaluate the effectiveness of DSDM technologies in practice (Kaplan, 2001a). However, in addition to my reflections about the benefits of the scenario-based approach, I have contributed an important reflection about using TAM for the evaluation of DSDM technologies in healthcare.

Researchers have used TAM as a tool to evaluate various healthcare technologies (as shown in Holden and Karsh (2010)). I found that the language used within published TAM questionnaires focused strongly on technologies that 'improve job performance', 'increase productivity', and 'increase effectiveness' of the user in their job. This was the case with healthcare studies using TAM also (Holden and Karsh, 2010). These concepts do not align well with the process of clinical decision-making, as it can be difficult to draw clear inferences about how the design of a medical device[8] influences clinical outcomes (Sharples et al., 2012). Therefore, evaluating the DSDM prototype in Chapter 4 based on its ability to improve the 'effectiveness', 'productivity', and 'performance' of the HCP was inappropriate.

To deal with these existing challenges within TAM, I worked iteratively with a Professor of Respiratory Medicine to adapt the TAM questionnaire provided by Davis and Venkatesh (1995) to ensure it was applicable to DSDM in healthcare. This involved changing the language of the statements to ensure that the responses were more pertinent and meaningful to DSDM. I actively avoided positioning the DSDM technology as a tool that would make HCPs more 'productive' workers, as this ignores the complex nature of clinical decision-making. The result of this process was

[8]Not all clinical dashboards are considered medical devices (GOV.UK, 2018). However, the challenges of associating a medical device with a clinical outcome can also exist when associating software with a clinical outcome.

a TAM questionnaire that was more relevant for evaluating DSDM technologies in healthcare. Holden and Karsh (2010) noted that researchers should better contextualise TAM quesionnaires for healthcare. As such, I contribute my critiques about TAM in healthcare and provide a contextualised TAM questionnaire used Chapter 4 in Appendix G.

Understanding and supporting reactive management approaches through design.

Chapter 5 (Technology and the Lived Experience) documented a rich account of the lived experience of chronic respiratory conditions (CRCs). This chapter discovered the ways that some people with COPD took a reactive approach to managing their condition, which contrasts with approaches that are more consistent and preventative in nature (Chapter 5, section 5.4.3.1, pg. 176). A statement by one participant summarises this phenomenon well: *"when I'm OK, I don't do anything, it's just when things go down I take action"* (Chapter 5, participant Nelly, section 5.4.3.1, pg. 177). Reactive approaches involved taking prescribed medication according to personal preferences instead of following instructions from HCPs, and having a desire to monitor symptoms only when feeling unwell. This approach was also seen with one patient in Chapter 6 (Self-Monitoring and Collaboration) in relation to taking antibiotics and the concerns about potential overuse (*"I know my body better than somebody writing prescriptions"* – Chapter 6, participant Robert, section 6.4.2.2, pg. 224). Though patients self-monitored consistently in Chapter 6, with no evidence of a reactive management approach taken, observing this phenomenon within that study's context would have been a challenge. This is because the study was small-scale (short duration and small number of participants) and any potential observer effect could have resulted in altered self-monitoring behaviour on the study (Sedgwick and Greenwood, 2015).

However, participants in Chapter 6 did report that the self-monitoring process would be more valuable during challenging seasonal periods or condition flare ups,

when there may be an increased motivation to self-monitor due to risks of poor health (Chapter 6, section 6.4.4.1, pg. 232) (Johnston et al., 2017; McManus et al., 2008; Sama et al., 2017). This reinforces the concept that engaging with self-monitoring technologies is perceived as more valuable during periods of flare ups, which may be infrequent. Overall the reasons for adopting a reactive management approach appeared to be related to the perceived unpredictability of the condition occurring regardless of taking medication (*"[you can do] everything you should ... [and still] have a bad day"*, Chapter 5, participant Tina, section 5.4.3.1, pg. 176), lack of perceived need to consistently take medication or monitor due to the condition appearing under control (*"if I was worse that would be different"*, participant Maggie, section 5.4.3.1, pg. 177) or believing that the severity of the condition does not warrant the medication prescribed (*"personally my body can cope without it"* – Chapter 6, participant Robert, section 6.4.4.2, pg. 224).

These findings around reactive management relate to behavioural research on how people self-manage COPD. Behavioural research has shown that health beliefs strongly influence how people self-manage and live with COPD (Arnold et al., 2011; Chambers et al., 1999; Dowson et al., 2004b; Kaptein et al., 2008, 2009; Rand, 2005; Restrepo et al., 2008; Salimi et al., 2013). According to the Health Belief Model used to explain health-related behaviours, 'perceived severity of the condition' and 'perceived benefits' (of taking action) are two theoretical constructs that are thought to influence health-related behaviour (Strecher and Rosenstock, 1997). Both constructs relate to the reasons why participants took reactive approaches to managing their COPD. From a medical perspective, reactive management approaches may contribute to worse health outcomes (e.g. if patients are not taking medication as prescribed (Makela et al., 2013)). However, this style of managing may not be as problematic for the practice of self-monitoring symptoms. Though this depends on the purpose of the self-monitoring activity.

It is not entirely surprising that some people with COPD may not want to monitor their symptoms during asymptomatic periods, as this may emphasise or remind people about ill health (Ancker et al., 2015; Craven et al., 2013; Lupton, 2013; Pols,

2014). In Chapter 4 (Data Supported Decision-Making) it was noted that the consistent monitoring of COPD symptoms may contribute to *"medicalising their condition"* (Chapter 4, participant C6, section 4.4.6.3, pg. 122). This demonstrates that HCPs, too, may have concerns about the effects of self-monitoring COPD symptoms each day. However instead of viewing self-monitoring as an activity that must be consistently and indefinitely 'complied' with, we can begin to consider how digital support could accommodated desires to reactively self-monitor symptoms.

In Chapter 5 I discussed how smart devices could support the generation of data points without the need for explicit user input (section 5.6.1, pg. 191). For example, smart inhalers could detect increased use and interpret this to mean that the patient feels unwell (Chen et al., 2020). Similarly, smart capabilities could be built into different devices or objects that users engage with when feeling unwell. Chapter 4 demonstrated some promise that a reactive approach to self-monitoring could generate clinically useful data. When discussing accessing patient-generated data on the prototype, HCPs discussed that *"there will also be patients who just don't put data in until they are unwell"* but the challenge would be if patients report *"greens [days of good health] but don't put the red [days of poor health]"* (Chapter 4, participant H5, section 4.4.6.3, pg. 123). This demonstrates that some HCPs would still find value in viewing patients' symptomatic days, even if asymptomatic days were not consistently captured. However, further studies are required to explore how technology could support capturing 'reactive' data and how this could generate reliable datasets that can be used for COPD care.

Designing for a personal and evolving condition journey.

As the related work in Chapter 2 showed, COPD is a complex chronic condition that introduces many physical and emotional challenges into peoples' lives. In Chapter 5 (Technology and the Lived Experience), I was able to explore how these challenges are experienced by people with COPD in their everyday lives. It became clear that the COPD journey is one that is highly personal and evolves due to the progressive nature

of the condition. Chapter 5 discussed the need to support the evolving needs of the condition, demonstrating how needs evolve in two main ways: (1) as individuals learn more about the condition through experiential knowledge and (2) as the condition progresses to a later stage in terms of severity (Chapter 5, section 5.4.3.2, 5.4.4.2, and 5.5.1.3).

Starting the condition journey required obtaining adequate 'clinical knowledge' and 'practical knowledge' about the condition (Pols, 2014). This knowledge was perceived to be an important aspect of being able to accept, and live with, COPD. Diagnostic uncertainty and lack of information from general practice staff marked the first point in the condition journey where many participants felt unsupported. Some participants believed that the lack of information from healthcare services was due to the stigma[9] around COPD: *"if they had been telling you that you had anything else, I don't think they would have just said that and sent you away"* (Chapter 5, participant Mary, section 5.4.1.1, pg. 171). Chapter 2 discussed the challenges relating to accurately diagnosing COPD in practice, including its similarities with asthma and the changes in medically agreed thresholds for spirometry results (Bellia et al., 2003; Buist, 2003; Fletcher and Pride, 1984; Murphy, 2019; Pellegrino et al., 2008; Tinkelman et al., 2006). Uncertainty around COPD diagnoses was also highlighted in Chapter 4 (Data Supported Decision-Making) relating to how some general practice staff formulate a diagnosis without conducting a spirometry test or may not be adequately trained to deliver these tests (section 4.4.2.2, pg. 99). Chapter 5 showed that these clinical uncertainties about COPD have an impact on how the patient is able to understand their condition. It is likely that as diagnostic tools and medical understanding about COPD improves in future, diagnoses and information about the condition will be more certain. However amidst the current uncertainty there is still a need to support patients' understanding of their condition.

[9]Recall that COPD was discussed as being a stigmatising condition due to its relations to cigarette smoking (Chapter 5, section 5.4.2.3, pg. 181).

Though participants felt that general practice staff did not provide them with enough information about their condition, it was noted that clinical knowledge needed to understand the condition could be obtained from COPD specialists. For example, specialists could provide detailed information about the condition and advice about how it should be managed. Specialists could *"explain exactly what the [clinical] tests mean"* (Chapter 5, participant Elliot, section 5.5.1.1, pg. 183) and *"could actually answer all your questions"* about the condition (Chapter 5, participant Rose, section 5.5.1.1, pg. 183). Referral to a COPD specialist, however, was not automatically offered as part of participants' care pathway. Therefore, participants discussed that it became their responsibility to actively seek this referral. This was a prominent point that led to workshop participants in Chapter 5 advising[10] a newly diagnosed patient to ask their GP *'would an early referral to a COPD specialist be useful?'* (Chapter 5, Group 2, section 5.5.1.1, pg. 183). Though this demonstrates the value that participants placed in receiving support from a COPD specialist, it also highlights the power of sharing collective experiences and advice across the CRC community to support the condition journey.

In fact, many participants in Chapter 5 credited practical knowledge sharing across the respiratory community as the reason that *"there's not anything I do not know about my lung condition, and inhalers, and how to look after myself"* (Chapter 5, participant Seb, section 5.4.1.2, pg. 172). Participants who attended support groups discussed them as a key avenue to obtain practical knowledge and ongoing emotional support about the condition – which was perceived as lacking from healthcare services[11]. There was, however, an acknowledgement that support groups are not accessible to everybody (Chapter 5, section 5.4.1.2 and 5.5.2.3, pg. 172 and

[10]Recall that in Chapter 5, workshop participants engaged in an activity about outlining important needs for the condition (section 5.2.4).

[11]It is important to note that as I recruited heavily from support groups in Chapter 5, the perceived benefits of these groups may be over-represented in my data.

188). It was thought that the reasons for this were: (1) lack of knowledge about the groups and barriers to advertising it; (2) being unavailable during the time of the group meetings[12]; and (3) being unable to physically attend the groups due to anxiety and mobility issues.

These challenges present an opportunity to consider how digital support could facilitate the dissemination of practical knowledge *"cowritten with people with COPD"* (Chapter 5, participant Mary, section 5.4.1.1, pg. 171). Previous work has engaged the Parkinson's community in the co-creation of health information resources – with information needs being commissioned from the community themselves – resulting in the creation of a radio channel which involved both clinical and personal perspectives (McNaney et al., 2018). Involving respiratory support groups in a similar way to co-create their own information resources could be a promising way to share practical knowledge. Moreover, this could help build a sense of community which traditionally resides in physical support groups. Collaborating with the CRC community in this way also ensures that community inclusive digital platforms are given precedence to.

I have discussed the importance of clinical and practical knowledge acquisition, particularly relating to starting the condition journey. However supporting the personalised and evolving needs of the condition was also discussed in relation to self-management technologies. Chapter 5 and Chapter 6 (Self-Monitoring and Collaboration) highlighted that people with COPD had a desire for technology to be personalised and adaptive to their condition journey. When recalling experiences of using the 'How Are You Today' app in Chapter 6, patients discussed the need for the mananagement advice generated by the app to relate to their personal context and capabilities. For example, providing insights and advice that relate to the specific behaviours of the patient rather than *"one message applies to all"* (Chapter 6, participant Robert, section 6.4.4.2, pg. 233). This was also raised in Chapter 5, as participants

[12] Recall participant Mary stating *"the majority of support for people with COPD is during the working hours"* (Chapter 5, section 5.4.1.2, pg. 172).

discussed abandoning self-management technologies when they no longer provided novel insights about their health (Chapter 5, section 5.4.3.2, pg. 178). As participants began to develop experiential knowledge about their condition they encountered different needs. For example, shifting from learning to understand the condition to predicting and preventing exacerbations. The need for technology to align with the evolving needs of the condition was summarised as *"[COPD] gradually gets worse, so the app needs to be personalised and change, and help people manage their condition so it doesn't get worse"* (Chapter 6, participant Robert, section 6.4.4.2, pg. 233).

Understanding how self-management technologies could support and accommodate the evolving needs of COPD has not been explored in previous work. Most previous research in this space has focused on supporting specific activities, such as rehabilitative exercises, monitoring the environment, or self-monitoring symptoms (Kim and Paulos, 2009; Pereira et al., 2016; Spina et al., 2013; Taylor et al., 2011). Though these are important activities for managing COPD, an opportunity exists to understand how technologies that aim to provide long-term support could be personalised and adaptive[13]. Johnston et al. (2009) acknowledged that this was an important area for future work as individual characteristics of people with COPD may shape different preferences to self-monitoring and management. Future research should work collaboratively with the CRC community to map out the condition journey to understand core needs at different stages[14]. This thesis contributes a starting point for this process, as I have identified a common challenge experienced by participants about starting their condition journey after diagnosis. This relates specifically to the need

[13]Algorithm transparency and explainability, as discussed in section 7.2.1, would be crucial in this context so that patients understand how the technology is personalised and adaptive

[14]It is important to note that people's lived experiences of COPD will be different. However, there may be common experiences across the community which could be supported by technology. For example as seen in Chapter 5, at early stages of COPD, people may be interested in self-monitoring to understand their symptoms. Whereas at severe stages of COPD, people may want to self-monitor and share this data with support networks to predict and prevent exacerbations.

for clinical and practical knowledge about the condition to help equip participants in their self-management and acceptance of the condition.

The 'safety net' paradigm involved with remote monitoring, and the challenges it introduces for HCPs.

Participants with COPD in Chapter 5 (Technology and the Lived Experience) and Chapter 6 (Self-Monitoring and Collaboration) highlighted a strong desire to share their symptom data with HCPs as part of their ongoing care and self-management. Sharing patient-generated data with HCPs in clinics and appointments was not something commonly reported by participants in Chapter 5. However it was discussed that participants would welcome this as part of self-monitoring their symptoms so that HCPs could be informed about their health outside of the clinic (Chapter 5, section 5.4.4.1, pg. 180). I discussed how including support networks in the self-monitoring process could help to alleviate reluctance that patients face in seeking help due to stigma and perceived burden (Chapter 5, section 5.6.3.1, pg. 197). This was reinforced in Chapter 6 as HCPs and patients themselves discussed how remotely sharing data about COPD symptoms could support seeking timely help (Chapter 6, section 6.4.1.2 and 6.4.2.1, pg. 221 and 222)

However in instances where HCPs *were* connected to data about patients' symptoms[15], they perceived themselves as *accountable and responsible* to monitor patients' health and identify health decline. This concept was discussed in Chapter 6 as 'shifts in responsibility of care', which HCPs felt occurred when they received patient-generated data remotely (Chapter 6, section 6.5.1, pg. 238). Detecting health decline was considered the responsibility of the patient as part of their self-management. However when HCPs are remotely connected to patients' symptom data, they felt detecting

[15]HCPs were connected to data about patients' symptoms in one scenario in Chapter 4 (Data Supported Decision-Making) and in Chapter 6 with patient-generated data from the case study.

health decline became their joint responsibility with the patient. As one HCP described in Chapter 4, having access to live symptom data means *"fundamentally they [the patients] aren't fully self-managing under this sort of scenario"* (Chapter 4, participant C6, section 4.4.6.3, pg. 122). While HCPs voiced that the implicit joint responsibility of detecting health decline was undesirable, patients described this as being a motivator to collect and share this data. Previous work has also identified that having HCPs connected to COPD symptom data is a strong motivator for patients to record this data (Brunton et al., 2015; Dahl et al., 2018; Nadarajah et al., 2019).

Previous telemonitoring studies observed how COPD patients *actively deferred* the responsibility of identifying health decline to HCPs (Fairbrother et al., 2013). Though this was not observed in Chapter 6, these concerns led to HCPs feeling reluctant to engage with the remotely received patient-generated data. In addition to this concern HCPs discussed the additional work that would be required to support this responsibility. In Chapter 4 HCPs raised concerns about how they would be expected to interpret missing data entries (Chapter 4, section 4.4.6.3, pg. 122). Whereas in Chapter 6 HCPs raised concerns about failing to act on potentially concerning data entries when occupied with other clinical duties (Chapter 6, section 6.4.3.1, pg. 225). A further challenge to note relates to how HCPs in Chapter 6 found themselves undertaking additional technical and medical duties to support the patients' use of the app (section 6.4.3.5, pg. 230). This was also seen as an undesirable outcome of engaging with technology that mediates data exchange between patients and HCPs.

Recall that self-management is understood as an 'individual's ability to manage the symptoms, treatments, physical and psychosocial consequences and life style changes inherent in living with a chronic condition' (Barlow et al., 2002). However self-management is also represented as a collaborative activity in the literature, involving varying levels of input from patients themselves, carers, and HCPs (Corbin and Strauss, 1984; Nunes and Fitzpatrick, 2015; Unruh and Pratt, 2008). When designing technology to support *self-management* activities, it is important to carefully consider the degrees of involvement that support networks should directly have. Increasing the responsibilities that support networks may traditionally have could clash with the

concept of self-management – in the sense that it is moving away from the 'individual's ability' (Barlow et al., 2002). In some situations increasing the responsibilities of support networks may be necessary, such as when a patient's abilities are progressively limited due to their condition (Nunes and Fitzpatrick, 2015). For example, the HCP may take on additional responsibilities such as calling the patient frequently to check on them. However, at this stage there becomes a transition away from 'self-management' as its described by Barlow et al. (2002). This raises an important question about the line where self-management 'ends' and a model that resembles more collaborative care 'begins'. The challenge in Chapter 6 was that this line was ambiguous.

Therefore it is important to consider the purpose of technologies that serve as a platform for patients to collect and share symptom data. For example is the intention of the technology to promote self-management or enhance collaborative care? If the former, how can these technologies be designed to keep the management responsibility on the patient? If the latter, how can these technologies be designed to alleviate the HCPs' concerns about potentially missing data entries and failing to act? To answer these questions it is important to work with patients, carers, and HCPs to co-create technology that considers the boundaries of responsibility. This presents an important opportunity for future work in this space to explore how we can design for the differences in self-management and more collaborative models of care.

Subjectivity and variability in personal health data can hinder decision-making.

To use personal health data to inform decision-making about patients' care, the data must be considered clinically reliable. Chapter 4 (Data Supported Decision-Making) and Chapter 6 (Self-Monitoring and Collaboration) unearthed challenges relating to the generation of reliable data about COPD symptoms. These concerns were mainly about the subjective nature of symptoms and how patients can vary in their judgement of their own symptoms (Chapter 4, section 4.4.6.3, pg. 124 and Chapter 6, section 6.4.3.2, pg. 226). Reporting the symptom 'breathlessness' was raised as the

most prominent cause of subjectivity as it can be influenced by anxiety and illness perceptions (Bailey, 2004; Carel, 2018; Heinzer et al., 2003; Maurer et al., 2008). However Chapter 6 also showed that increases in other symptoms such as 'sputum' and 'cough' may be judged variably and understood differently across patients (e.g. *"I'd call coughing up good not bad"* – Chapter 6, participant Lia, section 6.4.4.3, pg. 235). This demonstrates how there can be variability and subjectivity in COPD symptom data.

In clinic contexts it may be possible to decipher the root cause of certain symptoms when the patient is present to support the data interpretation process (Mentis et al., 2017). For example it was discussed that patient-generated data could be used in the clinic as *"an entry to a conversation"* to help the patient understand the cause of their symptoms (Chapter 4, participant C6, section 4.4.6.3, pg. 120). Though interpreting patient-generated data in the clinic has its own challenges (West et al., 2016, 2018; Zhu et al., 2016), when viewing this data remotely the patient is not present to support the interpretation process. Therefore subjectivity and variability in reports is more challenging to deal with. To seek clarification about remotely shared symptom data HCPs may be required to call the patient to discuss the data (Brunton et al., 2015). As highlighted in Chapter 4, contacting the patient to clarify observations in the data can generate *"a whole heap of work"* as *"you ring them up and they don't answer. Really common ... at some point, you are gonna have to send them a letter or do something else"* (Chapter 4, participant C6, section 4.4.6.3, pg. 123). Though this point by C6 was discussed in relation to clarifying missing data entries, it is relevant to the discussion about how HCPs can clarify uncertainties in remotely shared patient-generated data.

To combat the challenges relating to variability in subjective symptom reporting, Sanchez-Morillo et al. (2015) calculated a three day moving average of symptom reports instead of displaying them day by day. Likewise it was discussed in Chapter 4 that *"an agreed parameter where there was three days of red"* before the patient was highlighted as needing attention would help to establish when HCPs should take action (Chapter 4, participant H2, section 4.4.6.3, pg. 122). Considering how specific

thresholds in patient-generated data could be established to help HCPs manage their caseload should be explored in future studies. However it is also important to consider how minimising the variability and subjectivity in symptom reporting can be achieved through more reliable data capture. When unreliable data collection techniques are used, this gives rise to challenges relating to *overreacting* and *underreacting* to the data (Chapter 6, section 6.5.2.1, pg. 244). Pulse oximeter readings were discussed in Chapter 4 and 6 as providing a reliable baseline to compare and contrast patients' reported breathlessness. However Chapter 4 and Chapter 5 (Technology and the Lived Experience) showed that COPD introduces emotional and mental challenges that are important to share with support networks. Chapter 4 highlighted that there was clinical value in accessing subjective data about quality of life, as understanding the overall patient experience of the illness is important (Chapter 4, section 4.4.6.3, pg. 126). Patients may not be exacerbating but psychological difficulties may influence them to believe that they are (Dowson et al., 2004a). There is an important balance required to capture subjective data on *"what they [the patient] feel or experience"* and objective data on *"what is actually happening"* (Chapter 4, participant H4, section 4.4.6.3, pg. 126).

To capture objective *and* subjective aspects of breathlessness patients could record pulse oximeter readings and rate their experience of breathlessness on a clinically reliable scale. In instances where patients are reporting that they feel breathless across both scales, HCPs could interpret this as a potential sign of poor physiological health. In instances where patients have acceptable pulse oximeter readings but subjectively report feeling breathless, this could indicate that the patient requires psychological support. However it is important to highlight that increasing the amount of data that the patient is required to record can be burdensome (Ancker et al., 2015; Lupton, 2013). Different patient groups may have different levels of tolerance for

recording this data[16]. For example patients that are more severely unwell may feel the effort required to record this data is worth the benefit. However there is a still a need to consider what patients believe is important to track (and how) as part of the self-monitoring process. Future work should focus on co-designing self-monitoring technologies that incorporates both COPD patients' and HCPs' needs in terms of data collection (considering *what data* should be tracked *and how*). This can help work towards building support that considers the needs from both groups – avoiding tensions about chosen parameters to track (Zhu et al., 2016).

7.3 Positioning of Contributions

This section briefly summarises how my contributions can be positioned within existing research narratives in this space. I revisit the current body of relevant research from Chapter 2 (Background and Related Work) and briefly outline where I have added knowledge.

RQ1 - How can technology support healthcare professionals in their decision-making for COPD care?

The literature around DSDM in healthcare demonstrated a wealth of research focused on the development and quantitative evaluation of technologies that aim to support clinical decision-making. Dashboards featured strongly in previous work due to their ubiquity across healthcare settings (Dowding et al., 2015). Many studies on DSDM technologies focused on randomised control trials or evaluation studies, which aimed to assess the clinical effectiveness of DSDM dashboards. This strong focus prompted

[16] In Chapter 4, HCPs highlighted that the 'right' patient group would need to be identified to participate in collaborative self-monitoring. For example, patients who have just been discharged from hospital and require short-term monitoring (Chapter 4, section 4.4.6.3, pg. 120).

several scholars to call for approaches that better explored the (dis)use of these technologies from the user's perspective (Hartswood et al., 2003b; Heathfield, 2001; Kaplan, 2001a,b). There were a limited number of qualitative studies which involved HCPs during the design and evaluation of DSDM technologies to understand their true needs (Bardram and Nørskov, 2008; Sarcevic et al., 2018). However there was generally a lack of HCI research that sought to provide a rich understanding about the factors that influence how DSDM technologies are designed for, and used in, clinical settings. This understanding is crucial for providing insights that can support the design and deployment of DSDM technologies for real-world use in healthcare.

Though the challenges involved when innovating in the digital health space are well-researched (as shown in Fitzpatrick and Ellingsen (2013)). Prior to this thesis, these challenges were not specifically contextualised to technologies which support clinical decision-making. Through working with HCPs to design and qualitatively evaluate a DSDM 'dashboard' prototype in Chapter 4 (Data Supported Decision-Making), this thesis contributed this much needed contextualisation. I have provided rich insights about how we can approach the design of DSDM technologies that support respiratory care, taking into consideration the real-world challenges of clinical practice. This has progressed our understanding about the ways that DSDM technologies can support HCPs in their decision-making for COPD care.

RQ2 - What is the lived experience of COPD, and how can technology support this experience?

There were a relatively small number of studies that focused on building technologies that aimed to support COPD patients to manage their condition. However, prior to this thesis, there was very limited published work which had *systematically engaged* the CRC community to understand their lived experiences and how technology could support these experiences. Though there was existing research into the experiences of COPD and self-managing the condition (e.g. Cicutto et al. (2004); Cicutto and Brooks (2006); Giacomini et al. (2012); Pols (2010); Pols and Moser (2009); Seamark et al. (2004)), the findings from these studies had not been positioned within HCI litera-

ture to inform how self-management and self-care technologies should be designed. Chapter 5 (Technology and the Lived Experience) and Chapter 6 (Self-Monitoring and Collaboration) marked a starting point for HCI researchers to consider people's needs and lived experiences when designing technologies to support the COPD journey. Therefore, this thesis contributes a novel experience shared with the HCI community that heightens our understanding about designing for, and with, people with COPD. This thesis continues the turn in HCI research which considers the non-medicalised aspects of self-care by focusing on people's lived needs (Nunes and Fitzpatrick, 2015; Nunes et al., 2015). As such, this research has made an important step in advancing knowledge about how technology can support the lived experience of people with COPD (and CRCs more widely).

RQ3 - What is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals?

The literature review showed that the practice of self-monitoring one's health and sharing this data with HCPs is thought to support care and decision-making (Chung et al., 2016; Mentis et al., 2017; Schroeder et al., 2017; Zhu et al., 2016). Though this topic is of great interest to the HCI and medical community, most research about the patient experience of self-monitoring COPD focused on telemonitoring contexts (Brunton et al., 2015; Dahl et al., 2018; Huniche et al., 2013; Nadarajah et al., 2019). This is relatively unsurprising given that telemonitoring revolves around the practice of sending symptom data remotely to HCPs. However recording personal health data and sharing this with HCPs is not exclusive to telemonitoring, and it can occur as part of different social arrangements between patients and their HCPs. Overall there was a limited body of research in this space that sought to understand both the *patients' experience* of self-monitoring their COPD and the *HCPs' experience* of receiving this data. These joint experiences are crucial to report, and reflect, on so that digital support can incorporate the key needs of both groups. This is important for considering how these technologies can be used in the real world to support COPD care. I contributed to this gap in the literature through Chapter 6

(Self-Monitoring and Collaboration), where I explored the lived experiences of self-monitoring COPD symptoms and sharing this data remotely with HCPs. Taking this a step further, I provided novel design considerations that directly result from the reported experiences of both participant groups.

7.4 Chapter Summary

This chapter presented the overall discussion about my contributions to knowledge, drawing on the findings from each research chapter (4, 5, and 6). First, I reviewed the original aims and objectives of this thesis and outlined how I approached them. Then I demonstrated how the findings from the individual research chapters contributed to the overall understanding about the role of DSDM technology for respiratory care. Following this I presented a detailed discussion where I synthesised all the contributions of each research chapter. I concluded this chapter by summarising how my overall contributions can be positioned within existing research in this space, by briefly revisiting key research from Chapter 2 (Background and Related Work).

The next chapter is the final chapter of this thesis, which concludes this exploration of the role of DSDM technology for respiratory care. The chapter provides a high-level summary of the thesis contributions, opportunities for future work in this space, and final concluding remarks.

Chapter 8

Conclusion

This thesis has taken a user-focused approach to provide a rich understanding about the needs of those involved in Chronic Obstructive Pulmonary Disease (COPD) care. Particularly, this thesis has aimed to explore opportunities for data supported decision-making (DSDM) technology to support these needs and experiences. I have spent the past three years working in partnership with people directly impacted by COPD, so I could meaningfully explore this space and achieve the aims and objectives of this research. This chapter concludes my exploration of this area by providing a summary of my contributions to the fields of Human-Computer Interaction (HCI) and Health Informatics. Additionally, I outline opportunities for future work to further enhance understanding about the role of DSDM technologies for respiratory care. This thesis closes with concluding remarks that reflect on the research as a whole.

8.1 Summary of Contributions

Prior to this thesis there was a lack of understanding about the role that DSDM technologies could have for COPD care. The gaps in knowledge, identified from reviewing previous research (Chapter 2), led to the exploration of three research

questions in this thesis. These questions were: (1) how can technology support healthcare professionals in their decision-making for COPD care? (2) what is the lived experience of COPD, and how can technology support this experience? and (3) what is the lived experience of using self-monitoring technology to share symptom data between COPD patients and healthcare professionals? Below I summarise the main findings which have contributed to these three research questions:

1. My research in partnership with respiratory healthcare professionals (HCPs) and other healthcare stakeholders in Chapter 4 (Data Supported Decision-Making) has contributed the following:
    - A rich account of the daily challenges faced by HCPs relating to their decision-making about COPD care;
    - Insights into the trust concerns that HCPs have about certain data, which effects their confidence in its use for decision-making. Specifically, HCPs expressed distrust in certain data generated by other HCPs, patients, and data from particular clinical systems;
    - An understanding of the practical challenges of integrating DSDM technologies into existing clinical workflows. Particularly, understanding how HCPs should be trained on DSDM systems, how they should respond to data and insights, and what organisational protocols must accommodate the use of the new technology;
    - Critical discussion on the use of the Technology Acceptance Model for evaluating DSDM technologies in healthcare. This involved highlighting concerns about the criteria to which DSDM technologies for healthcare are judged;
    - Reflections on the strengths of scenario-based evaluations for DSDM technologies in healthcare. Particularly, how this technique can enable the capture of important sociotechnical factors which influence technology design and deployment.

2. Through my research engagements with the chronic respiratory conditions (CRC) community in Chapter 5 (Technology and the Lived Experience), I have contributed:

    - A rich understanding of the lived experiences of COPD, including the everyday challenges involved with self-care;
    - Insights about, and reasons for, the 'reactive' approaches that some people take to manage their CRC;
    - An identification of the need for self-care technologies to accommodate the gradual and evolving nature of the COPD experience, helping people to acquire the right support relative to their condition and experience stage;
    - Awareness about the need to design self-care technologies that can help and encourage people who face difficulties reaching out for support;
    - A recognition of the need to design and develop self-care technologies which are community inclusive and accessible. This is opposed to striving for concept 'novelty' that cannot fit into people's everyday lives.

3. The case study in Chapter 6 (Self-Monitoring and Collaboration) involved COPD patients self-monitoring their symptoms and remotely sharing the data with HCPs, which showed:

    - The 'safety net' paradigm that arises as patients feel comforted by HCPs viewing their symptom data, consequently creating concerns about accountability for the HCPs;
    - The trust concerns that HCPs have about patients' 'subjective' symptom reporting, and how this can negatively impact decision-making for both themselves and patients;
    - The strong need for algorithm transparency and explainability for HCPs to trust, and engage with, algorithms used in digital health technologies. Par-

ticularly, information about: who designed the algorithm, how it worked, what information it is based on, and how up to date this information is;

- The need for digital health technologies to adapt to local and individual contexts through personalisation. Specifically, considering the needs of local healthcare practices who support the technology and individual patients who use them.

8.2 Future Work

This section outlines the leading opportunities for future work in this space, which directly build on the findings and main limitations of this thesis.

8.2.1 Going Beyond 'Envisioning' Data Support

I used a scenario-based prototype in Chapter 4 (Data Supported Decision-Making) to explore how technology could support HCPs in their decision-making about COPD. This study provided important contributions about potential factors which influence how HCPs engage with DSDM technologies. Though I argue the scenario-based evaluation was a strength of this work, the evaluation focused on how HCPs could *envisage* using the prototype to support their decision-making. It is important to acknowledge that there is much more to learn here, particularly about how DSDM technologies are engaged with in clinical environments. The evaluations in this study were conducted in a quiet room that did not resemble the environment the technology would realistically be used in. As discussed in this thesis, there are notable challenges relating to integrating new technologies into healthcare systems. However, there are alternative approaches to further explore this space without integrating a fully functioning system into clinical practice (Favela et al. (2010) discuss a number of alternative methods which aim to strengthen the ecological validity of prototype evaluations).

Future work should explore how the scenarios in Chapter 4 may be used in clinic settings by introducing them within clinic appointments[1]. This would involve populating the scenario with real patient data (compared to dummy data used in Chapter 4), and observing how it is engaged with in clinic settings. This would help to understand how the technology may provide support in the environment it is designed to be used in. It would also provide insights about the real-time factors that influence its use and intended benefits. It may be challenging to adopt this approach for some scenarios explored in Chapter 4, such as Scenario 1 (an overview of COPD patients that are currently in hospital with a COPD related admission). However, exploring certain scenarios in clinic contexts is a useful starting point for furthering our understanding in this space. Ultimately, the goal is to understand how these technologies can be designed and deployed to support real-world use. Future work in this area would bring researchers and designers a step closer to building systems which achieve this.

8.2.2 Improving Personal Health Data Capture about COPD

Chapter 5 (Technology and the Lived Experience) explored the lived experience of COPD and how technology could support this experience. As part of that, there were discussions about how technology could support capturing personal health data about COPD for self-reflection, or sharing with trusted support networks. This study highlighted the need to design DSDM technologies that: operate on platforms inclusive to the CRC community; support reactive management approaches; evolve and personalise to the individual; and consider different levels and granularities of data sharing. However, an important next step is to explore how technologies which incorporate these factors are developed and used by people with COPD in practice.

[1]These clinic appointments could be organised as a research activity. They would still involve real patients and data.

Future research should build on these findings by conducting studies that test these concepts in-the-wild with people with COPD. Exploring how reactive data capture can be accommodated as part of self-monitoring would be particularly valuable. This would help to form an understanding about how this may support the lived experience of COPD without causing burden for user input.

As shown in Chapter 2, there have been a number of studies which have built novel technologies for COPD self-management (Anastasiou et al., 2018; Chatterjee et al., 2019; Fernandez-Granero et al., 2018; Merone et al., 2016; Nathan et al., 2019b). However, only a limited number of these studies have involved people with COPD in their research. Studies which expand on the research in Chapter 5 will be grounded in real needs observed within the CRC community. This will help grow the current limited body of HCI research working in partnership with, and for, people with CRCs to understand how technology can support them.

8.2.3 Exploring Personal Health Data about COPD in the Clinic

A prominent area that has not been explored in this thesis is how personal health data can be used in clinic appointments to inform COPD care. Chapter 6 (Self-Monitoring and Collaboration) explored the lived experiences of recording personal health data and sharing it remotely with HCPs. However, sharing data remotely and sharing in clinic contexts will introduce different challenges and opportunities for DSDM. A challenge when interpreting patient-generated data that is sent remotely is that the patient is absent from the interpretation process (Chapter 6, section 6.5.2.1, pg. 243). Observing how patients and HCPs collaboratively interpret COPD symptom data in clinic settings can provide important insights about how this data can inform care. Moreover, observing this collaborative activity provides insights about what is missing when HCPs interpret this data without the patient present (i.e. in remote contexts).

Understanding how patient-generated data is used and navigated in clinic set-

tings has been explored in previous HCI research (Chung et al., 2016; Mentis et al., 2017; West et al., 2016, 2018). However, these studies have not looked at patient-generated data about COPD specifically. Exploring COPD symptom data is important, as this thesis has demonstrated the potential complexities of this data for decision-making. For example, Chapter 4 (Data Supported Decision-Making) and Chapter 6 highlighted the challenges relating to the subjectivity of COPD symptoms. Whereas Chapter 5 (Technology and the Lived Experience) discovered the reactive management approaches that people may take when managing their condition. These factors have direct consequences for how symptom data should be collected and used for DSDM. Future work should seek to explore how data about COPD symptoms can be effectively used in clinic settings to support decision-making. Particularly, exploring what impact 'reactive' data capture has on decision-making in clinic settings.

8.2.4 Incorporating Carers' Perspective

Carers are a crucial pillar of support for patients with chronic conditions (Cameron et al., 2016; Corbin and Strauss, 1984; Nunes and Fitzpatrick, 2015; Seamark et al., 2004; Spence et al., 2008). In this thesis I focused on exploring the lived experiences of having COPD. Though I argue I was able to document a rich understanding of this lived experience, I acknowledge that carers' perspectives are largely missing from my work. There was a total of two carers who contributed data to this research. One participant in Chapter 6 (Self-Monitoring and Collaboration) was supported by his wife during the case study (section 6.3.3, pg. 217). She was able to provide valuable insights into the challenges that the participant faced living with COPD, including reflecting on his reluctance to seek help when needed. It is clear that carers can contribute a wealth of knowledge about COPD needs that may not be explicitly recognised, or admitted, by the person with the condition.

In addition to this, feelings of stigma and limited mobility could result in people with COPD feeling reluctant to participant in research. This potentially limits our understanding of the lives of people who could benefit from improved support. How-

ever, carers may be willing to share their experiences supporting people who face barriers to research participation. This can help build a wider understanding of the challenges and needs across the CRC community. Many participants with CRCs recruited in this thesis were members of support groups. Individuals without access to, or the desire to be part of, support groups require stronger representation. Therefore, future work could actively seek to incorporate carers' perspectives to build on this thesis[2].

8.3 Concluding Remarks

This thesis presented three novel pieces of research exploring the potential role of DSDM technology for respiratory care. I achieved this by working in partnership with people with COPD and respiratory HCPs. My findings have drawn on existing research within medical sciences, social sciences, and computer science to provide a rich understanding of what encompasses living with COPD and providing care for people with COPD. As a result, I have contributed an initial understanding of what influences decision-making about care in this space. From this, I have created a starting point for how DSDM technologies can be appropriately designed, deployed, and supported in practice. My methodological approach contributes to existing literature that has sought to demonstrate the power of qualitative research within digital health: taking a human-focused approach that complements the vast body of traditionally quantitative research in this space (Ackerman et al., 2017; Berg, 1999; Hartswood et al., 2003b; Kaplan, 2001a,b; Kaplan and Maxwell, 2005; Nunes and Fitzpatrick, 2015).

My work aimed to provide a rich understanding of my three research questions. Through doing so I encountered and explored various aspects of healthcare work

[2]It is important to note that recruiting carers is not a replacement for recruiting those who face barriers to participation. However, it can help to capture different perspectives (as well as offering perspectives specific to carers themselves).

and experiences of living with a chronic health condition. To an extent my research holds potential to contribute to digital health beyond the concept of DSDM. For example, my reflections and evaluation approach taken with HCPs in Chapter 4 (Data Supported Decision-Making) and Chapter 6 (Self-Monitoring and Collaboration) may inform how digital health technologies can be evaluated to truly appreciate their value and limitations. Likewise, my findings about respiratory self-care in Chapter 5 (Technology and the Lived Experience) and Chapter 6 could contribute to studies about COPD care pathway design. These would be considered secondary contributions of this thesis, which have not been my intended focus.

As I conclude this thesis it is important to re-emphasise that this has been a very challenging space to plan and conduct research, as discussed in detail in the methodology (Chapter 3). There were numerous challenges to navigate: obtaining ethical approvals; recruiting participants; conducting research activities; and practical ethical implications evident on reflection. These types of challenges are inherent with conducting research in the healthcare space, a domain that is less tolerant to errors and risk. The challenging nature of conducting research in this space is partly why it can take many years for research to translate into clinical practice (Liddell, 2007; Morris et al., 2011; Topol, 2019). As such, this PhD marks an important starting point for understanding the role of DSDM technology for respiratory care — laying the foundations for future work to further enhance this understanding. There remains a vast amount of knowledge to discover that can bring us closer to the successful intersection of medicine and computer science, in a way that supports the care for a growing population of people (Barnes, 2007).

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Appendix A

Chapter 4: Participant Information Sheet and Consent Form

This section includes the participant information sheet and consent form used to recruit participants for Chapter 4.

Participant Information Sheet

Project Title: Co-Designing Health Systems
Researchers: Helena TendeDez
Principal Investigator: Prof Jon Whittle, Head of Department, School of Computing and Communications, Lancaster University. Email: j.n.whittle@lancaster.ac.uk

About the research
Connected Health Cities is a project designed to unite local health data and advanced technology to improve health services for citizens in North West England. As part of this project, at Lancaster University, we are working on co-designing software systems with clinicians, which will utilize NHS data to aid better clinical decisions to be made. The systems that are designed will support clinicians in the North West of England to improve patient and experience.

About the team
The researchers in this team are part of the School of Computing and Communications at Lancaster University.

Why have you been approached?
You have been approached to take part in this project because you are a clinician who has experience with patients who suffer from chronic obstructive pulmonary disease (COPD), or have an interest in improving care or services for these patients. For this reason, we would like to interview you or invite you to a focus group to discuss this. You have the opportunity to contact the researchers during or after the study, face to face or via email, for any reason.

What does 'Informed Consent' mean?
Before the study commences, you will be asked to sign a consent form to confirm that you have read and received this information sheet and that you are willing to volunteer in this research. You do not have to take part in this study if you do not want to. You have the right to terminate the interview at any point and you are not obliged to answer questions if you do not wish to. You may withdraw from the research without any negative consequences. If you wish to withdraw from this research, please do so within two weeks of the interview, so that the interview material can be excluded from the analysis.

Recording sound
We would like to take audio recordings of the interviews, group discussions and workshops. These audio recordings will be transcribed. Parts of the recordings may be used in publications, such as newspapers, written reports, public presentations, and on the Lancaster University website and respective social media channels. Your name, email or

contact addresses will not be used without your explicit consent. In addition, we are committed to withhold any data that could be used to identify you, such as employer name, address, etc. Therefore, no one will be able to identify you.

Photographs
We would like to take photographs of workshops and discussions. If you agree, photographs may be used in publications such as newspapers, essays, reports, public presentations or websites including the Lancaster University website and its social media channels.

Confidentiality and anonymity
All information collected from you will be treated with confidentiality. This means that only the research team will have access to any of the raw information that can be specifically associated with you. Any information that is shared beyond this team will be anonymised. Your name and address will be removed, and we will use a pseudonym to refer to you instead. This will apply to any publication or presentations or any discussions with other colleagues in the University. Data that can be used to identify you will also be removed. We will keep personal details (such as your name and contact email, if you provide this) and research content (e.g. interview transcriptions) in separate encrypted and password protected files.

How will the data be used and protected?
We will treat data that you have provided in accordance with the Data Protection Act 1998. This means that any personal information stored in physical format (paper, readily playable recordings) will be stored in a locked filing cabinet in a locked office in Lancaster University premises. Any personal information that is stored electronically will be stored on a secure and password protected server. Any personal information that is transported electronically on a mobile device (such as a laptop) will be encrypted and/or password protected. The information collected will be used to inform the development of further research and may be included in publications, presentations and PhD theses. Only anonymised information will be retained indefinitely for on-going research purposes. We will keep the raw data for up to 10 years after the data is collected, after that, the data will be destroyed.

Who has reviewed the project?
This study has been fully reviewed by the Faculty of Science and Technology Research Ethics Committee. If you have more questions please contact Helena TendeDez, School of Computing and Communications, Room C20, C Floor, InfoLab21, Lancaster University, Lancaster LA1 4WA, via email at h.tendedez@lancaster.ac.uk.

Issues or complaints
If you have any concern about this study wish to speak to someone outside study, you may contact:
Prof. Awais Rashid, Director of Research, School of Computing and
Communications C41, InfoLab21, South Drive, Lancaster University, Lancaster LA1 4WA, UK
Tel: +44 (0)1524 510316
Email:
marash@comp.lancs.ac.uk

Participant Consent Form

Project Title: Co-Designing Health Systems

Name of Participant: _____

Pseudonym to be in research: _____
(Please leave blank if you prefer the researchers to select a pseudonym)

The purpose of this consent form is to check that you understand what till be required of you, if you agree to take part in this research, and how any information you give will be used in the study.

1. I confirm that I have read and understood the Participant Information Sheet for the above study. ☐
2. I have had the opportunity to consider the information, ask any questions about the research and have had these questions answered satisfactorily. ☐
3. I agree to participate in this study. I understand that my participation is voluntary and I can choose to opt-out of the study at any time as described in the Participation Information Sheet. ☐
4. I understand that I have the right to withdraw, without giving any reasons for this, at any point during the study. ☐
5. I agree for any interviews I give to be audio recorded. ☐
6. I agree that photographs of me can be taken. ☐
7. I agree that any quotations from what I say during an interview can be used in publications. I understand that my quotations will be used anonymously. ☐
8. I understand that any personal data I provide will be retained and processed by the researcher in accordance with the Data Protection Act 1998. ☐
9. By providing contact details, I understand that I will be contacted further by the team with updates about the study. ☐

Participant email/phone number: _____ *(optional)*

Participant's signature: _____

Researcher's signature: _____

IRAS 223318 – 29/06/2017

Date: _____

Appendix B

Chapter 4: Stage 1 Requirements Document

This section presents the document that I created about the early data requirements from the Stage One one-to-one interviews held in Chapter 4.

Stage One

Problem Scoping Interviews

This document outlines the high-level data requirements discussed in the stage one interviews between HT and H3, H4 and C6. The requirements have been divided into data requirements (Table 1), functional requirements (Table 2), and non-functional (Table 3) to provide structure to the document.

Data requirements refer to specific data that participants mentioned they would like access to when using the dashboard.
Functional requirements refer to the what the system should do (the behaviour of the system)[1]. **Non-functional requirements** refer to how the system should work from a quality perspective [2].

Table 1. Data requirements

No.	Requirement	Supporting statements
1	Hospital admission data.	*"For forward planning."* [H3] *"We don't know how many patients are at any one point in the hospital, if we don't know how many are admitted, be it COPD or any other disease associated ... we want to flag that up."* [H3] *"Once we know from a secondary care perspective, we can see what can be done to avoid admissions."* [H4] *"See how admissions are changing over time."* [H3]
2	Flu jab data for different locations.	Having updates on areas that have/have no had flu jabs, reported by various schemes already. This would allow the targeting of areas that have slow or low uptake in flu jabs to plan for action. [C6]
3	Information on clinic letters such as symptoms and flare ups for individual patients	*"There's information relating to symptoms and flare ups that are collected in clinic letters, on GP systems, as well but we don't really have access at the moment."* [H3]
4	Weather, pollen and pollution data.	*"Would be incredibly useful"* and is collected by the MET office [C6].
5	Patient generated data around symptoms.	Through using mobile health apps that allow patients to collect data on their symptoms [C6].
6	Patient smoking status across different locations.	Smoking status and smoking rates would be useful to collect [C6].
7	Indicators of COPD status at both a population level and individual patient level basis.	*"Ideally we'd like to be able to look at population data, what's happening for specific indicators as it were, then be able to go down to individual GP practice, organisation, down to individual patient."* [H3]

[1] Dabbagh, Mohammad & Lee, Sai. (2014). An Approach for Integrating the Prioritization of Functional and Nonfunctional Requirements. The Scientific World Journal. 2014. 737626. DOI: 10.1155/2014/737626.
[2] Ibid

Table 2. Functional requirements

No.	Requirement	Supporting statements
1	Present data in summary form.	*"I just want to know what is common with people 60+ female? Looking at this [month/days] admissions, etc., that's what I expect to get from the dashboard. Is it 60+ females? What's the average length of stay, when have we intervened, has this reduced their stay? That's my vision."* [H4]
2	Visualise trends and patterns in COPD data.	*"Looking at patterns... is it more in weekends or weekdays? Is there a pattern or if it's just a scatter of data then we need to crack out heads again and figure out what's causing them coming into hospital?"* [H4] *"Looking at a pattern and then look into what will cause that pattern."* [H4] *"If there is a pattern that there is issues with the way things are being managed, or admissions or whatever from a particular practice – we can look down to see the issues there."* [H3]
3	Collate COPD data held by different organisations.	*"I have to physically ask the GP to fax, why can't I see the [spirometry test investigation] on my screen if there is one? If it's all in a cloud somewhere I can tap into those resources and see that information which will help me make further decisions when it comes to A&E that is not available at the moment"* [H4]
4	Highlight potential deficiencies in service.	*"If one month we aren't doing so well on smoking cessation, we can think, well, why is that? Is there a reason? Is a member of staff off? Is there been a change in the way we approach that target?"* [H4]
5	Utilise existing data sources to visualise routinely collected data.	It would be "*extremely helpful*" to utilise existing data sources to avoid having to collect and input new data [C6]. *"So there's information collected in clinic letters, when a patient has seen their GP as well, so that's information relating to symptoms and flare ups that's collected in clinic letters, on GP systems as well but we don't really have access at the moment."* [H3]
6	Have a responsive way of checking that beds are free.	Clinicians have to make phone calls sometimes to find out if a hospital is full as can't access this information online which is "*incredibly time consuming.*" [C6] Check if number of beds are going up or down as this data is often obtained one month later and needs to be checked on the go as clinicians are often not in one place [C6].

Table 3. Non-functional requirements

No.	Requirement	Supporting statements
1	Visualise data in a user-friendly format for decision-making.	*"Being able to look at the data in a user-friendly format across the health economy will help us identify areas that we need to work on."* [H3] *"Most systems aren't user-friendly. They're quite clunky and you have to go through lots of processes to get where you want really."* [H3] *"Visualising data in an easy way will absolutely help me do my job"* [C6]
2	Dashboard should be pervasive.	Clinicians are often not in one place, so being able to access the dashboard from different places is helpful [C6]. *"I am not a very IT person, I am not comfortable with that, I prefer desktop. The only other way to go would be on a mobile computer that we use on the wards."* [H4]
3	Inform decisions that can make a meaningful change for patients.	*"We are hoping this [dashboard] will make a meaningful change to the patients."* [C6]
4	Minimise extra work associated with data input.	*"Data entry is incredibly manual and takes too much time for admin ... it's important to be realistic, they do not have time to manually input data."* [C6]
5	Utilise data in real time.	*"Be more proactive instead of waiting for data to come through" [H3]* *"A lot of the data we have, or the information we have is retrospective. So months behind. But in order to be able to act when things are fast moving, particularly in the winter months when things are busy for us as well so we can really focus on particular aspects of care or particular systems in the organisation - if that happens in a real time way, so we can see that on a day to day or week to week basis."* [H3]
6	Visualise data quickly to help assess whether interventions are effective.	*"[Certain] knowledge will help us manage better." [H4]* *"I think having a dashboard would mean we are able to assess any quick interventions that we put in, so any change we make, PDSA cycle, if we have something that reacts to whatever we put in the patient's pathway, in terms of detecting any changes in admissions or whatever it might be then it would help forward planning a bit more and help with how we develop the services further."* [H3]
7	Minimise duplication of data to keep report writing procedures efficient and less time consuming.	Reporting information about beds for example could be minimised with a live dashboard displaying this information [C6]. A system that minimises duplication and can match up data. [C6]
8	Visualise service data to allow decision-making based on data and metrics.	*"Identifying the specifics is quite difficult, we need to focus on the details ... the way we are set up is quite fragmented ... there's a lot of data out there" [H3]*

Appendix C

Chapter 4: Stage 2 Priorities Workshop Document

This section presents the document that I created that summarises the data from the Stage Two workshops held in Chapter 4.

Stage One

Priorities Workshop

This document outlines the discussions around data priorities for the dashboard from the priorities workshop with H3, H4, C9, IT1, BI1 and BI2.

Table 1. Focus Group One

Priority	Aim	Label	Supporting Statements
Access to admissions data, with the ability to identify periods where there are spikes in admissions.	To decrease the number of admissions by identifying periods of spikes and acting upon those spikes (by deploying more community nurses, etc.) Use the dashboard to understand if admissions rates are lowered as a direct result of actions taken.	***High priority***	*"I think spikes in admissions, being able to track spikes in admissions, and being able to deploy the services, so get in reach from the community team and for us to be able to focus our efforts in the trust to a particularly area, that's quite a big priority I think for us as a trust, to be able to decrease the number of admissions we are getting in, so, if we are able to do that I think that's a high priority."* [H3]
Access to data behind the admissions numbers, such as: are the admissions reoccurring for certain patients, where an admission has come from geographically, are admissions occurring from a particular practice.	Understanding what practices most admissions are coming from will allow assessments of that practice/location to take place to understand why admissions numbers are so high.	***High priority***	*"The patterns around it would be interesting as well. So, if we get a spike, what is it about those patients that are coming in, are they patients who have had reoccurring admissions that are all coming from a particular area of the city, or particular practice?"* [H3]
Access to spirometry data, such as spirometry test results and diagnosis data.	The respiratory clinicians are currently unsure about the quality of spirometry tests carried out in primary care so repeat these tests when they see a patient.	***Medium priority***	*"We have issues with diagnostics at the moment around spirometry and things, so that should be fairly soon really, be able to access disease specific data if you like, so spirometry data as part of this."* [H3] *"There's been a big change in the way people are trained to deliver spirometry and we don't really have any idea about quality of spirometry across the patch and also equipment upkeep and servicing type of stuff."* [H3] *"Because of the data sharing we may or may not get a photocopy of some spirometry, when a patient comes to the clinic, but also it's about the quality of that data, I can't really be sure that it's correct."* [H3]

Accessing patient reported data to understand symptoms and predict admissions.	Access to patient reported data on a mobile health app or similar device to help the clinicians predict potential admissions and better understand how a patient is managing.	***Blue sky thinking***	*"The other thing that's quite exciting, I think, going forward, it's probably blue sky actually... patient reported data? And how to link that into all of this, so the data that patients record around symptoms, either on paper or electronically using the app."* [H3] *"It may be doable in 3-5 years, but I think we have a long way to go to be able to get patients to record the data, I think that's going to be the issue. I think the cohort of patients that we deal with are generally not very electronic, kind of savvy, as it were. So using smart phones and things but that will change... you know... people get older... using patient reported data to, and whether that could predict any of these admissions and so on."* [H3] *"I think the key to identifying these admissions and things is around the patient reported data because we know patients do delay and put off seeing their doctor in case they go to hospital and there's research to show that, if we can push that back then we can potentially make quite a big impact."* [H3]
Identify patients reaching end of life (last 12 months of their life) and share their priorities with GPs on a digital system.	End of life patient discussions happen in meetings and are recorded on paper. This makes it difficult to share a patient's priorities as they reach end of life with their GP and others. Building this into a system would be helpful to share this data across services.	***Blue sky thinking***	*"Our expanding cohort of patients with very severe disease who are in the last 12 months of their life, being able to effectively have their data available to everybody so that's viewable in the community and hospital etc and we can effectively respond to their needs as well."* [H3] *"We are identifying patients proactively who reaching the last 12 months of their life and are trying to manage them more effectively, so I think if we can look at that as well. We could go all standard frameworks, patients who – I don't know if you have heard of that, if you hit certain disease in generic criteria which predicts that they are in the last 12 months of their life, and that will enable us to maybe focus on slightly different priorities for the patients maybe."* [H3] *"There is data, the data that is generated in our meetings where we discuss all the patients are just on paper at the moment, it gets photocopied and mailed out to GPs, so if that could be built into Quadramed [our main system] we could do that as we go along in the meeting and that could be fed into this and that would be really helpful"* [H3]

Table 2. Focus Group Two

Priority	Aim	Label	Supporting Statements
Trace COPD misdiagnoses to understand what practices require support.	Understanding where misdiagnoses take place will allow practices to be targeted for support. This will in turn help to improve how patients are diagnosed and the quality of that diagnosis.	***High priority***	*"I'm not a clinician, but in the few conversations that I've had, about spirometry, there does seem to be some consensus that the quality of spirometry depends on where the patient has attended that test, is higher in some areas than others. And when the quality isn't particularly high, that's where you end up with patients that are misdiagnosed."* [BI1] *"If we could just look at that, that in itself would make a massive difference, not just to the number of inappropriate referrals that we'd have to accept anyway because they technically they've been diagnosed with COPD, but also from the patient perspective as well because it then puts the patient on the pathway that they might not need to be on."* [BI1]
Understand pulmonary rehabilitation rates and which practices are referring patients to that service.	Identifying practices that are not referring patients into pulmonary rehabilitation can enable them to be targeted and educated about the benefits of referring patients (and the available resource). Understanding the number of patients being referred can help with planning resources for the activity.	***High priority***	"*Yes, there is [the desire to see which patients are being referred into PR], from us, not with current funding. We've just had a recent resurgence in referrals because there's been pressure applied to surgeries who haven't previously referred, it's difficult to manage, we're just managing."* [C9] "*Who is delivering treatment, those patients that should have been referred to PR that haven't been, what resources are needed to see these patients in total that haven't been referred. If you can visualise it all, it would help commissioners as well to a degree because they'd be able to visualise what happens now but what needs to happen."* [BI1] "*I think overall management, like you know pulmonary rehab would come there and number of admissions they had in the last one year so that we can target them specifically you know their ongoing management towards that, unfortunately it's a progressive condition so if I start seeing that there are more and more admissions or more and more complications then it tells me that I need to start advanced care planning*" [H4]

Spirometry test results	Secondary care clinicians cannot see spirometry test results that were taken in primary care, often having to repeat them due to this inaccessibility of data.	***High priority***	*"We can't see it, you have to beg borrow and ask somebody to contact what is the spirometry? You can't see that unless they have had a spirometry as part of their investigation in chest clinic for which we will have some data but you know, I think it's being done, it's just we can't see it, even when the GP sends somebody's care records, even then we can't see it, we have to ask them specifically what was their spirometry."* [H4] *"[I want] the graphs which would give us the information and the values as well, it depends on the age for that patient, what is the percentage predicting, etc."* [H4] *"Definitely to see a trend to say that things are getting worse and we need to do something about it now because it is a progressive disease and once we start seeing the downhill then we need to know we need to put more services on, more into the actual management of the patient."* [H4]
Create disease specific predictions about the patient population and individual patients based on current data	Use machine learning to predict patient outcomes based on different management techniques to allow for more effective management decisions and resource allocation.	***Blue sky thinking***	"*I think it's sometimes scary to even dream of this… to be able to visualise pictorially what is happening to our COPD service, I think that is my dream goal, by then I've done my immediate diagnostics I got everything right, most of it right, and managed them, so I can kind of predict 5 years down the line this is what my COPD patient population will be, for planning it would be like 'wow this is what I need'."* [H4] *"Because you know at the end of the day I want it down to that patient Mr Smith but strategically or from a service point of view how many Mr Smiths are in this area or in this, you know, population that is what datasets, to me, that is what the dataset is doing, it's telling me how many similar patients that are in that situation and in this area so that I can target my intervention in that particular area so that I can get the management right in that place, to me all this dataset is trying to help me achieve that."* [H4]

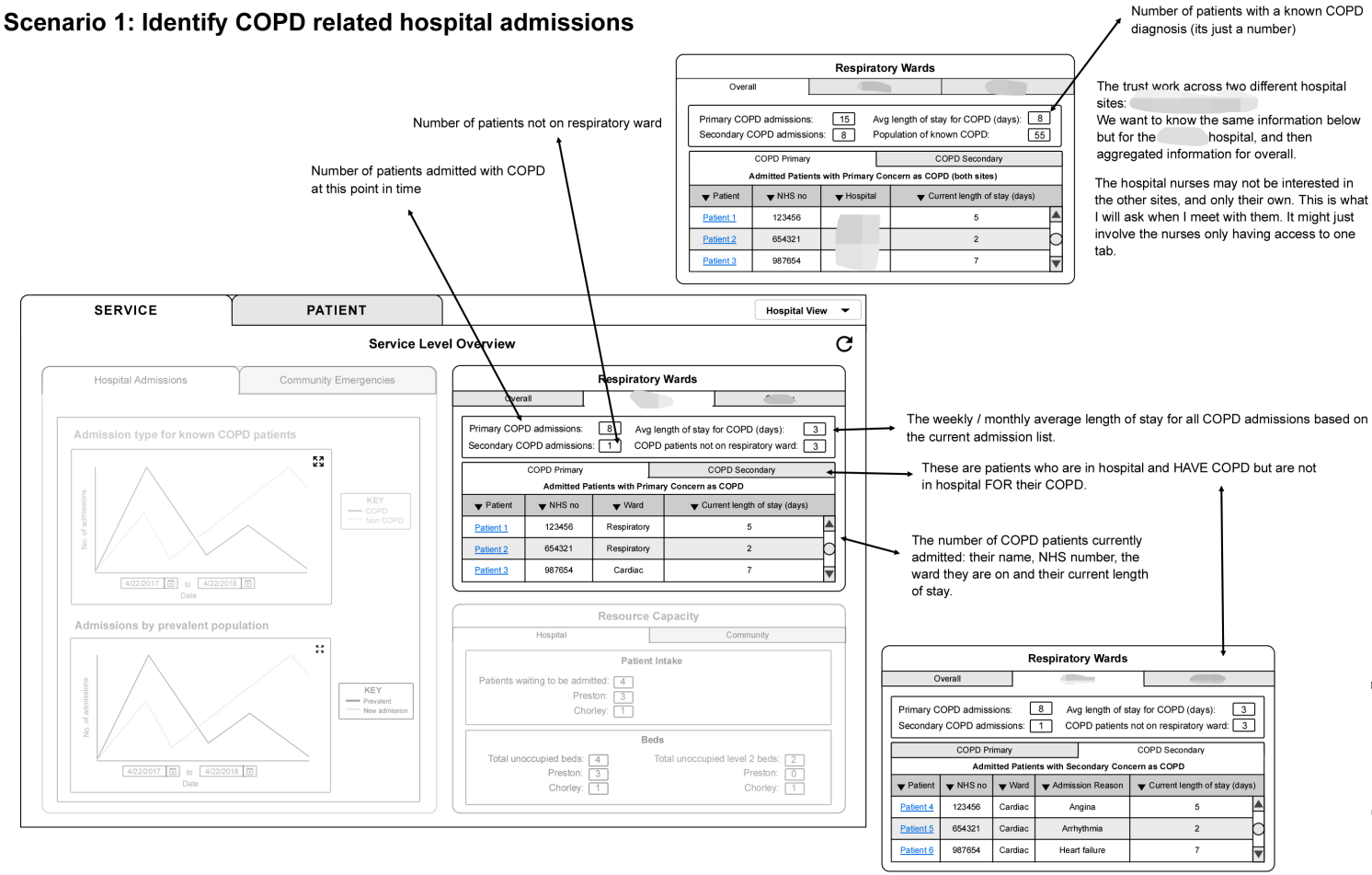
Appendix D

Chapter 4: Early Annotated Wireframes

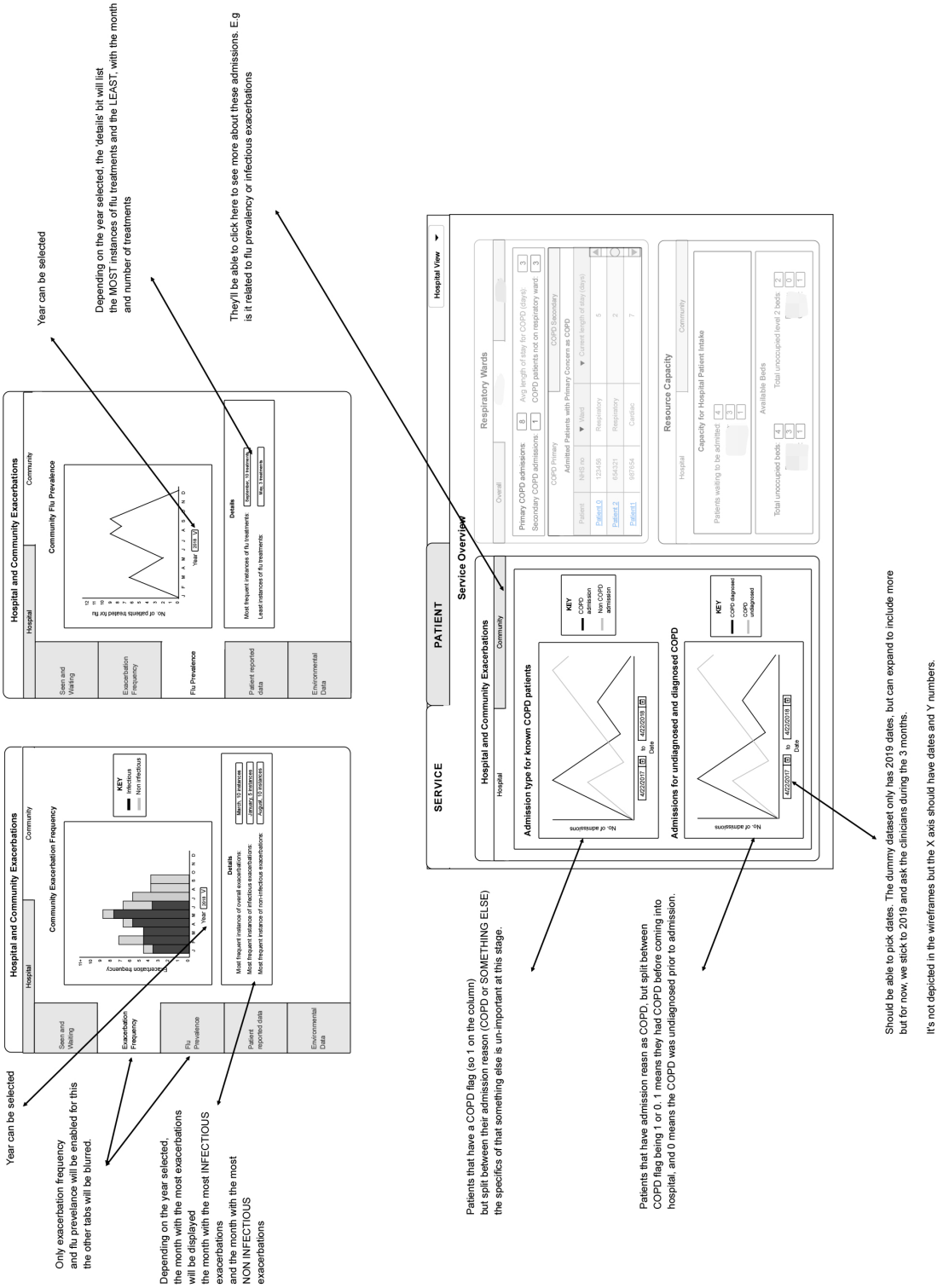
This section presents early versions of annotated wireframes used in the development process of the prototype in Chapter 4.

D.1 Wireframe for Scenario 1: Respiratory Ward Overview

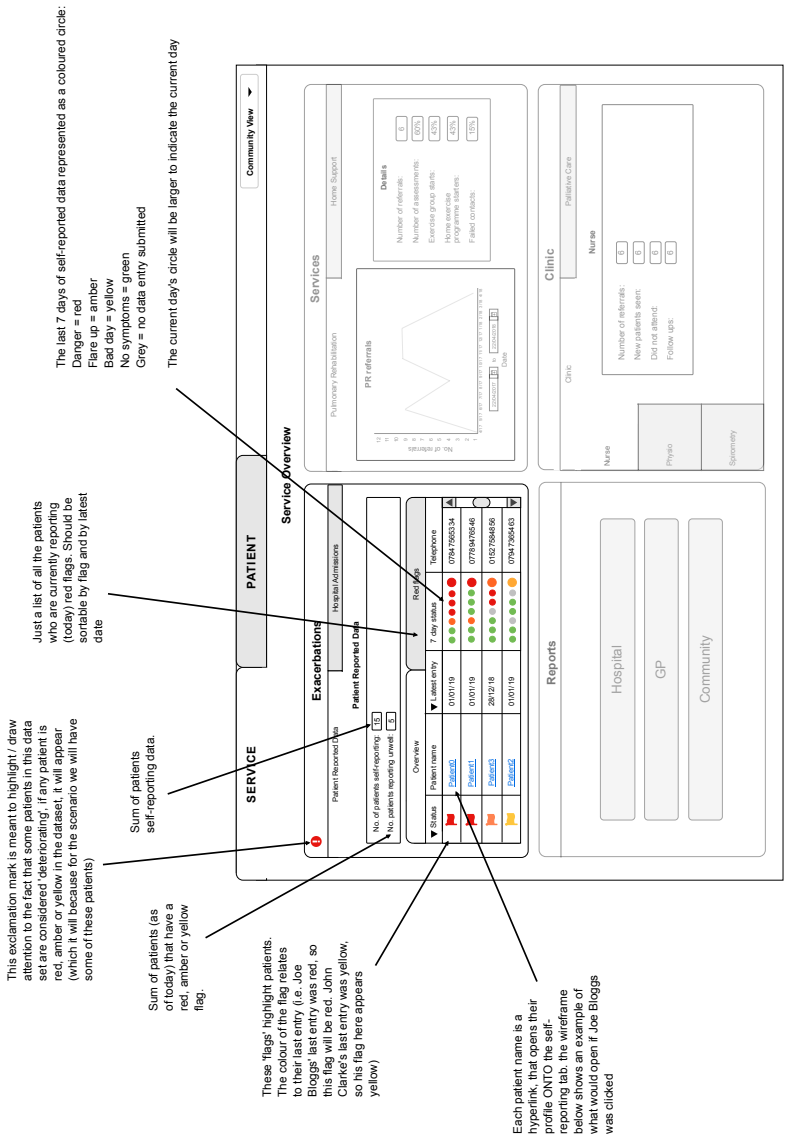
Scenario 1: Identify COPD related hospital admissions



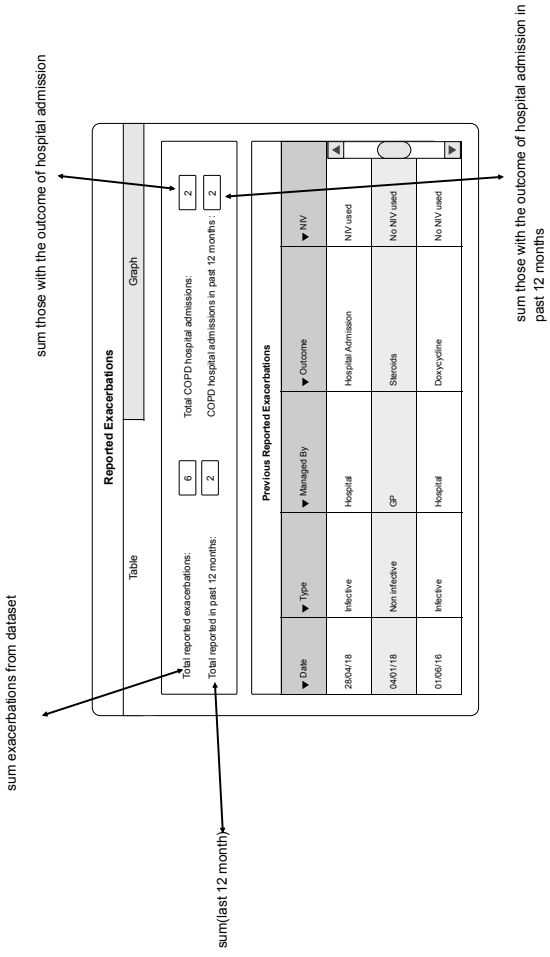
D.2 Wireframe for Scenario 2: Admissions and Exacerbation Reports



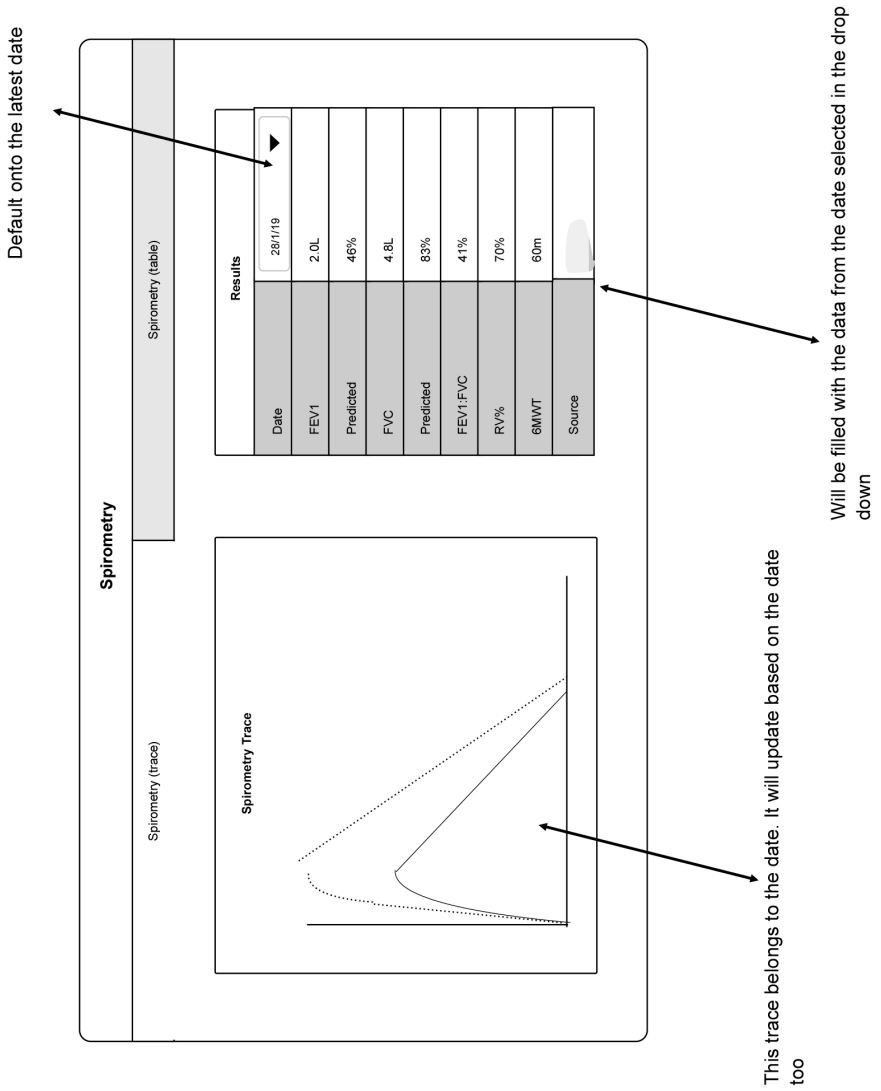
D.3 Wireframe for Scenario 3: Patient-Generated Data



D.4 Wireframe for Scenario 4: Example Patient's Exacerbation History



D.5 Wireframe for Scenario 5: Example Patient's Spirometry Results



Appendix E

Chapter 4: Scenario Dummy Datasets

This section presents information about the schema for the dummy datasets that I created for the prototype in Chapter 4.

Scenario 1 Dummy Dataset

This dummy data set was created based on hospital admissions data. The 'COPD Flag' column is based on the Hospital's marker system, and relates to if a patient is on the marker system or not.

I created approximately 20 dummy patients for this scenario to simulate a realistic number of COPD in-patients.

Patient	Previous COPD admissions	NHS Number	Bed Number	Hospital Number	Admission Date	COPD Flag	Ward Location	Admission Site	Admission Reason
Patient0	1	1234	1	5432	01/01/19	1	Respiratory	Hospital1	COPD

Scenario 2 Dummy Dataset

Dummy dataset **A** breaks down infective and non-infective exacerbations recorded by the three sites, Community Care, Hospital, and GP.

I created approximately 180 dummy data points for dataset A, 344 dummy data points for dataset B, and 180 dummy data points for dataset C. The rationale behind the numbers was simply to simulate enough time series data that could be engaged with on the prototype.

A	Date	Community_ NonInfective	Community_ Infective	GP_ NonInfective	GP_ Infective	Hospital_ NonInfective	Hospital_ Infective
	01/01/19	1	3	0	6	2	9

Dummy dataset **B** aggregates COPD admission numbers over time.

B	Patient	Admission Date	COPD Flag	Admission Reason
	Patient0	01/01/19	1	COPD

Dummy dataset **C** breaks down the number of flu vaccinations administered over a period of time

C	Year	Month	Flu_Vaccinations_Administered
	Patient0	January	5

Scenario 3 Dummy Dataset

This dummy data set is based on patient-generated data from the smartphone app 'How Are You Today' (for monitoring of COPD). The 'Day_Type' column is generated as a result of the user's input. The 'Action_Taken' column indicates what the user has done that day in relation to their COPD (e.g. taken their medication). 'SymptomReport3' is a rating of their breathlessness, 'SymptomReport4' is a rating of their cough, 'SymptomReport5' is a rating of their sputum, and 'SymptomReport6' is a report of their sputum colour.

I created five dummy patients for this scenario. For each individual patient, I created approximately 50 dummy data points about their symptoms to simulate enough time series data for the evaluation.

Patient	Date	Day_Type	Action_Taken	Symptom Report3	Symptom Report4	Symptom Report5	Symptom Report6
Patient0	01/01/19	Bad	Increased Inhaler Use	Increased Breathlessness	Increased Cough	Increased Sputum	Normal

Scenario 4 Dummy Dataset

This dummy dataset breaks down the date of an exacerbation, which healthcare service managed it, the type of exacerbation (infective or non-infective) and the outcome.

For this scenario, I created 8 dummy data points to simulate a realistic exacerbation history that one patient might have.

Date	Managed_By	Exacerbation_Type	Outcome
01/01/19	Hospital	Infective	Hospital Admission

Scenario 5 Dummy Dataset

This dummy dataset includes a patients' spirometry test results, followed by the date, and the source of the test (Community Care, Hospital, GP Practice).

For this scenario, I created 4 dummy data points to simulate a realistic spirometry test history that one patient might have.

Date	FEV1	Predicted	FVC	Predicted	FEV1:FVC	RV%	Source
01/01/19	2.3L	46%	4.8L	69%	59%	70%	Hospital

Appendix F

Chapter 4: Scenario Usefulness Ranking Results

This section presents the results from the scenario usefulness ranking survey provided to participants as part of the evaluation in Chapter 4.

	Participant											
Scenario	H1	H2	H3	H4	H5	C6	C7	C8	C9	C10	C11	Average
1: Respiratory Ward Overview	1	1	4	1	4	1	2	1	3	5	1	2.18
2: Admissions and Exacerbation Reports	2	4	5	4	3	2	4	4	5	4	5	3.81
3. Patient-Generated Data	2	5	2	5	1	5	3	3	4	1	2	3
4. Example Patient's Exacerbation History	1	2	1	2	2	3	5	2	1	2	3	2.18
5. Example Patient's Spirometry Results	1	3	3	3	5	4	1	5	2	5	4	3.27

A score of 1 indicates most useful and a score of 5 indicates least useful. Note that participant H1 insisted on ranking some scenarios equally.

Table F.1: Results from the usefulness ranking activity.

Appendix G

Chapter 4: TAM Questionnaire

This section provides a template of the TAM questionnaire used in the Chapter 4 prototype evaluation.

Perceptions of Dashboards

1. **Using data dashboards to improve patient care, management and service provision is a good idea.**

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

2. **Using data dashboards to improve patient care, management and service provision would be beneficial for how I manage patient care.**

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

Perceived Usefulness

1. **Using respire would give me more evidence – and so help improve my decision making.**

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

2. **Using Respire would save me time compared to my current practices.**

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

3. **Using Respire may lead to more effective patient care overall.**

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

4. **Respire would be of practical use for my work.**

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

Perceived Ease of Use

5. **My interaction with Respire is clear and understandable.**

Strongly	+3	+2	+1	0	-1	-2	-3	Strongly

	Agree							Disagree

6. Interacting with Respire does not require a lot of my mental effort.

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

7. I find Respire easy to use.

Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

8. I find it easy to get Respire to do what I want it to do.

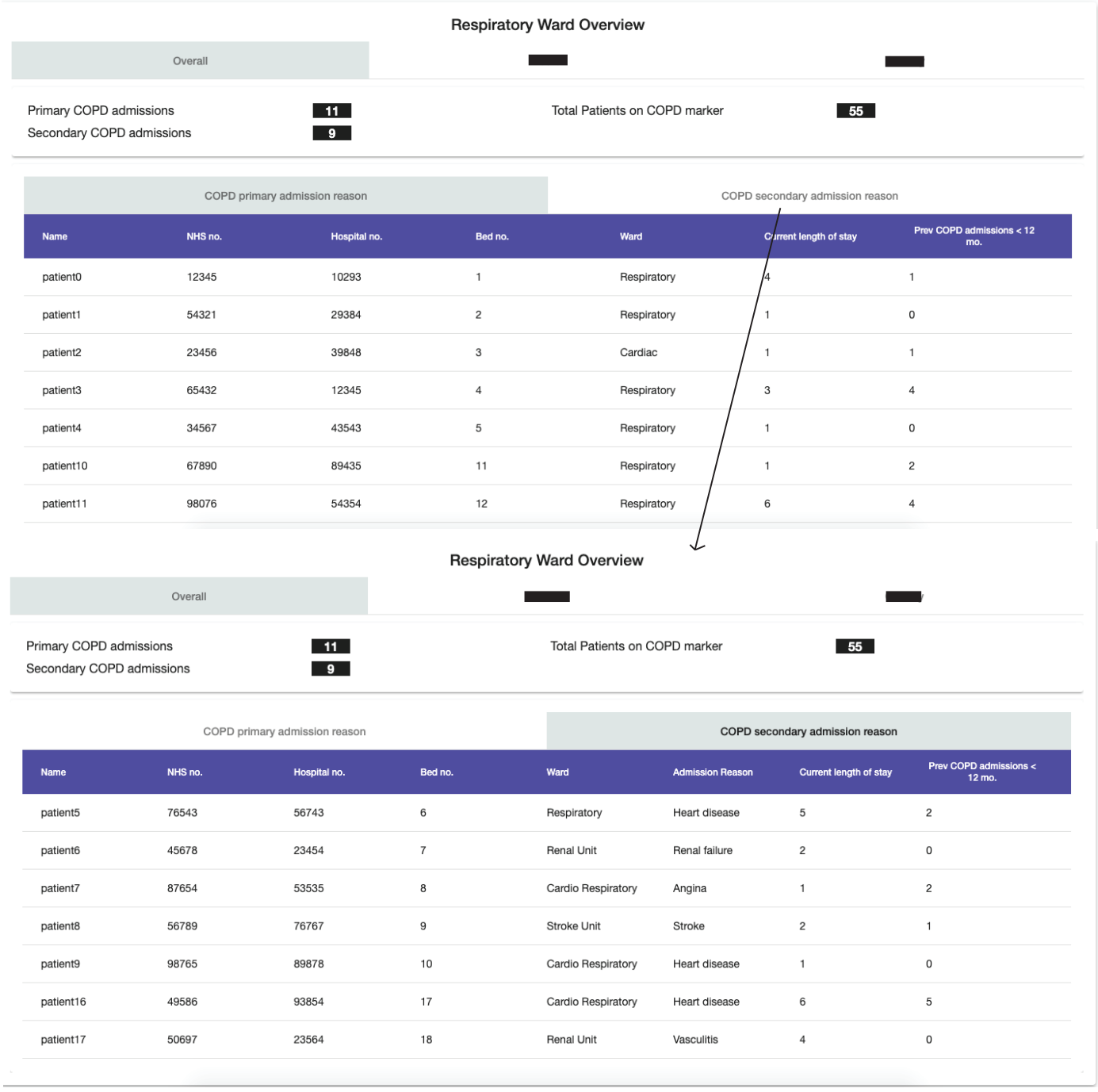
Strongly Agree	+3	+2	+1	0	-1	-2	-3	Strongly Disagree

Appendix H

Chapter 4: Scenarios Included for Evaluation

This section includes details of the five scenarios shortlisted for inclusion in the digital prototype as part of the Chapter 4 evaluation.

H.1 Scenario 1: Respiratory Ward Overview



Respiratory Ward Overview

Overall

Primary COPD admissions 11
Secondary COPD admissions 9

Total Patients on COPD marker 55

COPD primary admission reason

COPD secondary admission reason

Name	NHS no.	Hospital no.	Bed no.	Ward	Current length of stay	Prev COPD admissions < 12 mo.
patient0	12345	10293	1	Respiratory	4	1
patient1	54321	29384	2	Respiratory	1	0
patient2	23456	39848	3	Cardiac	1	1
patient3	65432	12345	4	Respiratory	3	4
patient4	34567	43543	5	Respiratory	1	0
patient10	67890	89435	11	Respiratory	1	2
patient11	98076	54354	12	Respiratory	6	4

Respiratory Ward Overview

Overall

Primary COPD admissions 11
Secondary COPD admissions 9

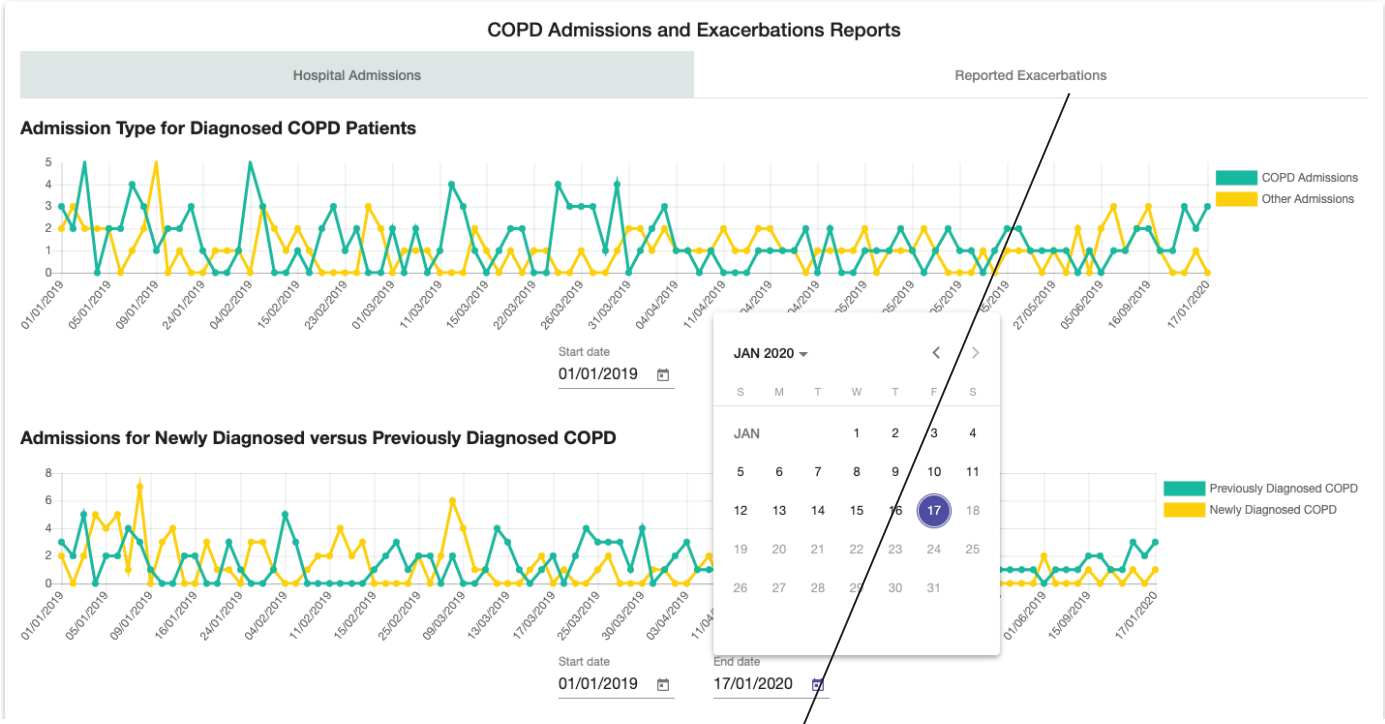
Total Patients on COPD marker 55

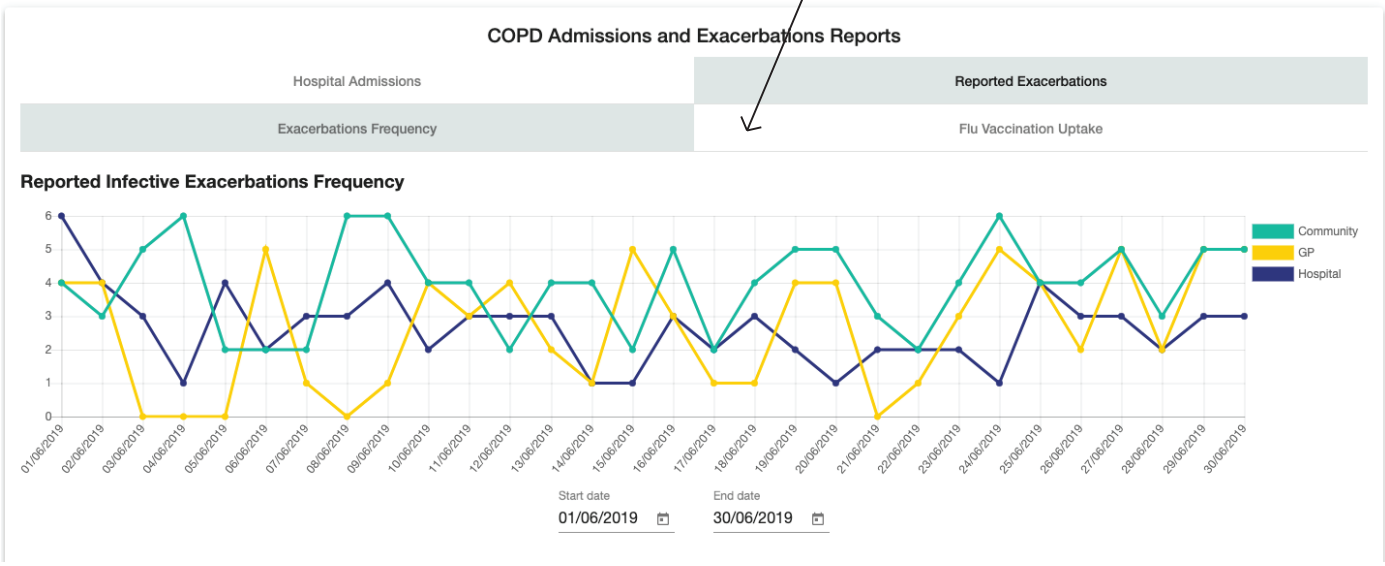
COPD primary admission reason

COPD secondary admission reason

Name	NHS no.	Hospital no.	Bed no.	Ward	Admission Reason	Current length of stay	Prev COPD admissions < 12 mo.
patient5	76543	56743	6	Respiratory	Heart disease	5	2
patient6	45678	23454	7	Renal Unit	Renal failure	2	0
patient7	87654	53535	8	Cardio Respiratory	Angina	1	2
patient8	56789	76767	9	Stroke Unit	Stroke	2	1
patient9	98765	89878	10	Cardio Respiratory	Heart disease	1	0
patient16	49586	93854	17	Cardio Respiratory	Heart disease	6	5
patient17	50697	23564	18	Renal Unit	Vasculitis	4	0

H.2 Scenario 2: Admissions and Exacerbation Reports



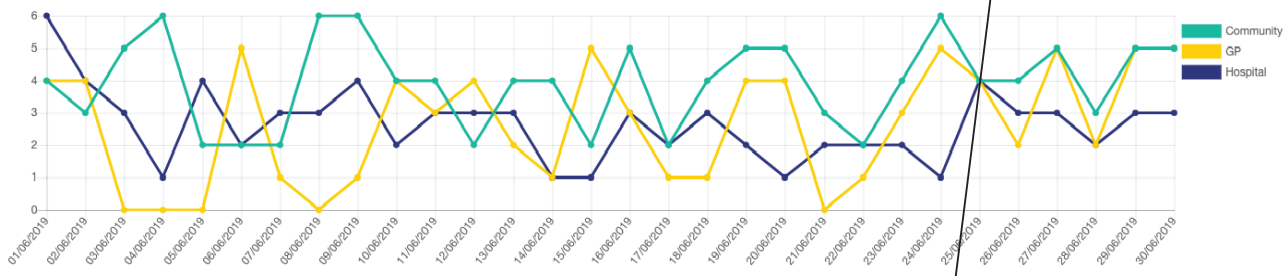


COPD Admissions and Exacerbations Reports

Hospital Admissions | **Reported Exacerbations**

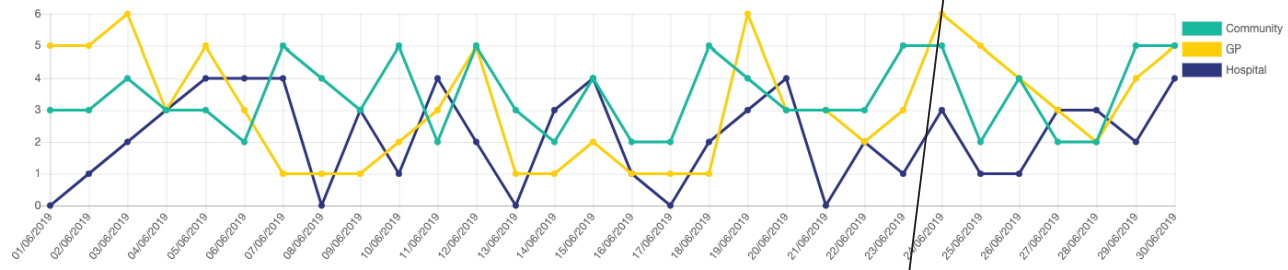
Exacerbations Frequency | Flu Vaccination Uptake

Reported Infective Exacerbations Frequency



Start date 01/06/2019 End date 30/06/2019

Reported Non-Infective Exacerbations Frequency



Start date 01/06/2019 End date 30/06/2019

Details

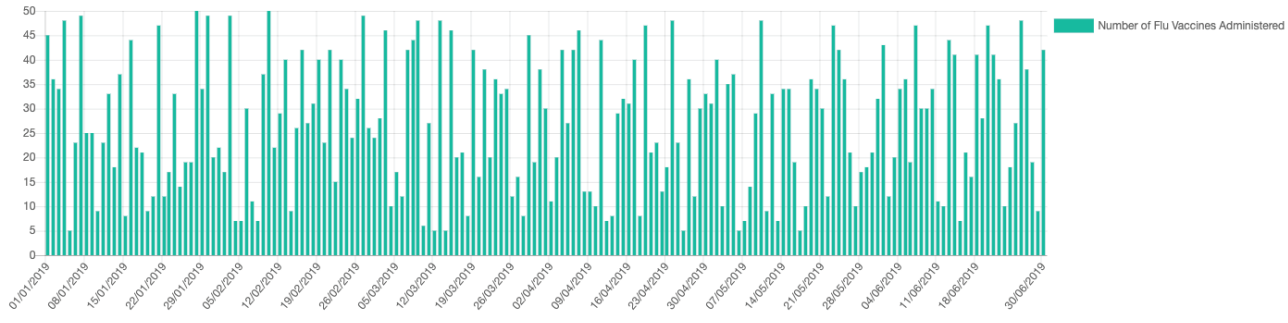
Most frequent instance of overall exacerbations	**24/01/2019, 55 instances**
Most frequent instance of infective exacerbations	**24/01/2019, 42 instances**
Most frequent instance of non-infective exacerbations	**20/03/2019, 18 instances**

COPD Admissions and Exacerbations Reports

Hospital Admissions | Reported Exacerbations

Exacerbations Frequency | **Flu Vaccination Uptake**

GP Reported Flu Vaccination Uptake



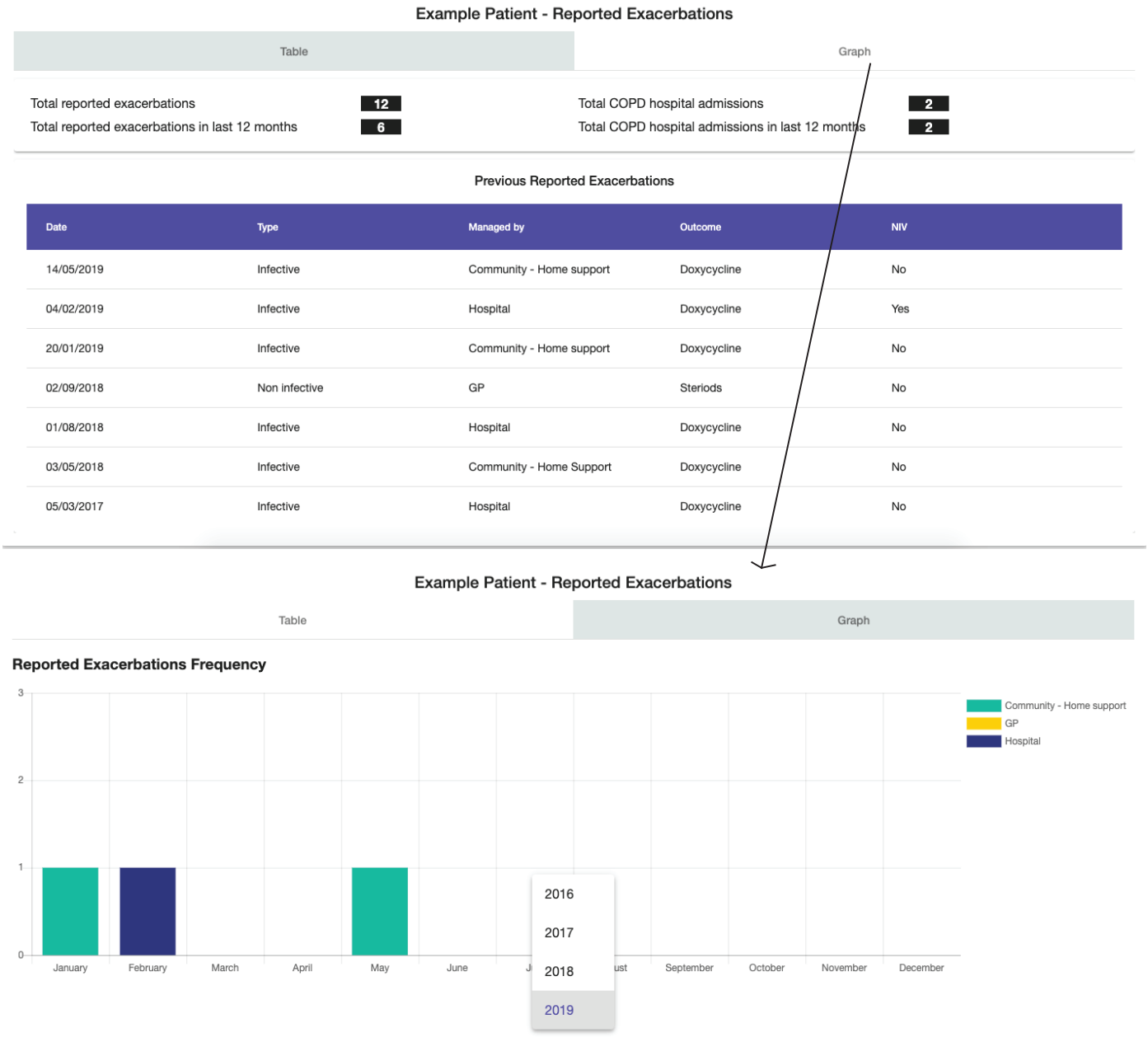
Start date 01/01/2019 End date 30/06/2019

Details

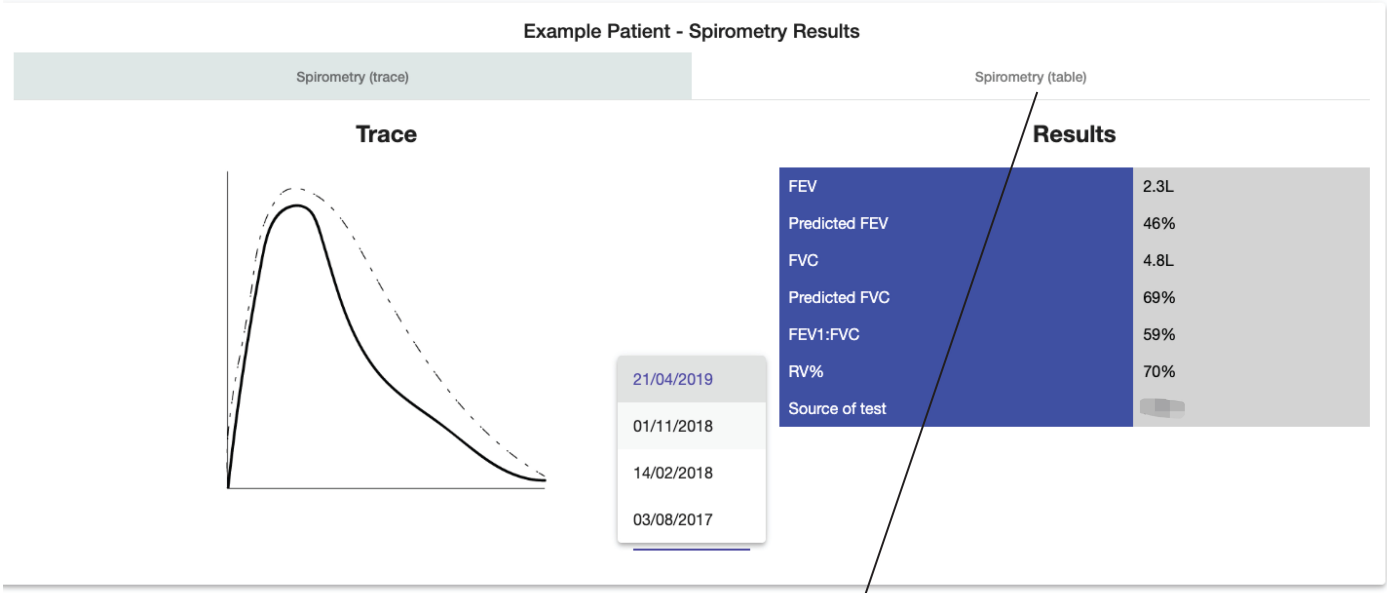
Most frequent instances of flu treatments	**28/01/2019, 50 treatments**
Least instances of flu treatments	**05/01/2019, 5 treatments**

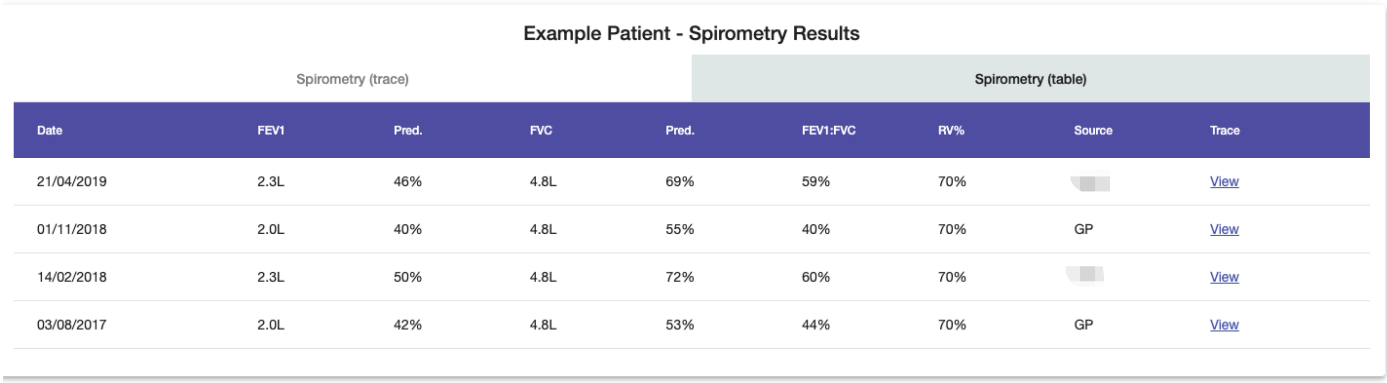
H.3 Scenario 3: Patient-Generated Data Overview

H.4 Scenario 4: Example Patient's Exacerbation History



H.5 Scenario 5: Example Patient's Spirometry Test Results





Date	FEV1	Pred.	FVC	Pred.	FEV1:FVC	RV%	Source	Trace
21/04/2019	2.3L	46%	4.8L	69%	59%	70%		View
01/11/2018	2.0L	40%	4.8L	55%	40%	70%	GP	View
14/02/2018	2.3L	50%	4.8L	72%	60%	70%		View
03/08/2017	2.0L	42%	4.8L	53%	44%	70%	GP	View

Appendix I

Chapter 5: Participant Information Sheet and Consent Form

This section provides the participant information sheet used to recruit participants for Chapter 5.

Participant Information Sheet

Project Title: How Are You Today?
Researchers: Helena Tendedez, Roisin McNaney, Maria-Angela Ferrario
Principal Investigator: Roisin McNaney, Lecturer in Digital Healthcare Technologies School of Computing and Communications, Lancaster University.

About the research
Connected Health Cities is a project designed to unite local health data and advanced technology to improve health services for citizens in North West England. As part of this project, at Lancaster University, we are working on co-designing software systems with clinicians, which will utilize NHS data to aid better clinical decisions to be made. The systems that are designed will support clinicians in the North West of England to improve patient and experience.

About the team
The researchers in this team are part of the School of Computing and Communications at Lancaster University.

Why have you been approached?
You have been approached to take part in this project because you have an understanding of chronic obstructive pulmonary disease (COPD) or other respiratory conditions, the care of these conditions and the lives of people affected by the condition. For this reason, we would like to interview you or invite you to a focus group to discuss this. You have the opportunity to contact the researchers during or after the study for any reason.

What does 'Informed Consent' mean?
Before the study commences, you will be asked to sign a consent form to confirm that you have read and received this information sheet and that you are willing to volunteer in this research. You do not have to take part in this study if you do not want to. You have the right to terminate the interview at any point and you are not obliged to answer questions if you do not wish to. You may withdraw from the research without any negative consequences. If you wish to withdraw from this research, please do so within two weeks of the interview, so that the interview material can be excluded from the analysis.

Recording sound
We would like to take audio recordings of the interviews, group discussions and workshops. These audio recordings will be transcribed. Parts of the recordings may be used in publications, such as newspapers, written reports, public presentations, and on the Lancaster University website and respective social media channels. Your name, email or contact addresses will not be used without your explicit consent. In addition, we are

committed to withhold any data that could be used to identify you, such as employer name, address, etc. Therefore, no one will be able to identify you.

Photographs
We would like to take photographs of workshops and discussions. If you agree, photographs may be used in publications such as newspapers, essays, reports, public presentations or websites including the Lancaster University website and its social media channels. We will not be publishing photographs of participants without their explicit consent.

Confidentiality and anonymity
All information collected from you will be treated with confidentiality. This means that only the research team will have access to any of the raw information that can be specifically associated with you. Any information that is shared beyond this team will be anonymised. Your name and address will be removed, and we will use a pseudonym to refer to you instead. This will apply to any publication or presentations or any discussions with other colleagues in the University. Data that can be used to identify you will also be removed. We will keep personal details (such as your name and contact email, if you provide this) and research content (e.g. interview transcriptions) in separate encrypted and password protected files.

How will the data be used and protected?
We will treat data that you have provided in accordance with the Data Protection Act 1998. This means that any personal information stored in physical format (paper, readily playable recordings) will be stored in a locked filing cabinet in a locked office in Lancaster University premises. Any personal information that is stored electronically will be stored on a secure and password protected server. Any personal information that is transported electronically on a mobile device (such as a laptop) will be encrypted and/or password protected. The information collected will be used to inform the development of further research and may be included in publications, presentations and PhD theses. Only anonymised information will be retained indefinitely for on-going research purposes. We will keep the raw data for up to 10 years after the data is collected, after that, the data will be destroyed.

Who has reviewed the project?
This study has been fully reviewed by the Faculty of Science and Technology Research Ethics Committee. If you have more questions please contact Helena Tendedez, School of Computing and Communications, Room C20, C Floor, InfoLab21, Lancaster University, Lancaster LA1 4WA, via email at h.tendedez@lancaster.ac.uk.

Issues or complaints
If you have any concern about this study wish to speak to someone outside study, you may contact: Prof. Nicholas Race, Director of Research, School of Computing and Communications
D33, InfoLab21,
South Drive, Lancaster University,
Lancaster LA1 4WA,
UK Tel: +44 (0)1524 510123
Email: **n.race@lancaster.ac.uk**

Lancaster University

Participant Consent Form

Project Title: How Are You Today?

Name of Participant: _____

Pseudonym to be in research: _____
(Please leave blank if you prefer the researchers to select a pseudonym)

The purpose of this consent form is to check that you understand what till be required of you, if you agree to take part in this research, and how any information you give will be used in the study.

1. I confirm that I have read and understood the Participant Information Sheet for the above study. ☐
2. I have had the opportunity to consider the information, ask any questions about the research and have had these questions answered satisfactorily. ☐
3. I agree to participate in this study. I understand that my participation is voluntary and I can choose to opt-out of the study at any time as described in the Participation Information Sheet. ☐
4. I understand that I have the right to withdraw, without giving any reasons for this, at any point during the study. ☐
5. I agree for any interviews I give to be audio recorded. ☐
6. I agree that photographs of me can be taken. ☐
7. I agree that any quotations from what I say during an interview can be used in publications. I understand that my quotations will be used anonymously. ☐
8. I understand that any personal data I provide will be retained and processed by the researcher in accordance with the Data Protection Act 1998. ☐
9. By providing contact details, I understand that I will be contacted further by the team with updates about the study. ☐

Participant email/phone number: _____ *(optional)*

Participant's signature: _____

Researcher's signature: _____

Date: _____

Appendix J

Chapter 5: Survey Questions

This section provides the survey questions used in Chapter 5.

1) What chronic respiratory conditions do you have?

Asthma COPD Bronchiectasis Bronchitis Emphysema I'm not sure
Other, please specify

2) How long have you lived with a chronic respiratory condition?

Less than one year 1-5 years 6-9 years 10+ years

3) What gender do you identify with?

Woman Man In another way

4) What is your age range?

40 or under 41-55 46-50 51-55
56-50 61-65 66-70 71-75
76-80 81-85 80 or over

5) Where do you live?

Scotland Wales Northern Ireland South East England
Ireland North West England North East England South West England
Midlands Other, please specify

6) Which of the following devices do you own?

A basic mobile phone (with limited capabilities) Landline telephone (home phone)
A smartphone (such as an iPhone or Android phone) A computer or laptop
Game consoles (such as PlayStation or Xbox) A tablet (such as an iPad)
Smart watch (such as Fitbit or Apple watch) I don't own any of these devices

7) What do you use the following technologies for?

	Sending and receiving email	Messaging family and friends	Browsing the Internet	Shopping online	Social networking	Playing games	Other things
A smartphone (such as an iPhone or Android)							
Laptop or computer							
Tablet (such as iPad)							

8) What is the biggest challenge that you face living with your respiratory condition(s)?

9) What social support do you have available to you?

Paid carer Family Friends Support group members
The community team at my local healthcare service I have no social support
Other

10) What techniques or methods do you use (or have you tried in the past) to manage the symptoms of your respiratory condition? Please select all that apply

Taking prescribed medication including inhalers
Following an exercise plan or attending exercise classes
Keeping a diary of your symptoms and reflecting on the diary
Attending support groups (such as Breathe Easy groups)
Taking readings through a peak flow meter and reflecting on these readings
Taking readings through a pulse oximeter and reflecting on these readings
Attending pulmonary rehabilitation groups / classes
Other, please specify

11) **How many times in the past two years have you been admitted to hospital for your respiratory condition?**

None 1-2 times 3-5 times 6+ times

12) **How do you currently share details of your symptoms and general wellbeing with your clinician during appointments? For example do you show them diary notes that you have made on how you've been feeling, oximeter readings, mobile health app data you've collected, or just verbally discuss how you've been feeling?**

13) **How confident would you say you are using technology?**

Not confident at all Somewhat confident Very confident I'm not sure

14) **Have you ever used any form of technology to help manage your respiratory condition? Please select all that apply.**

Yes, I've used a dedicated smartphone app
Yes, I've taken pulse oximeter readings
Yes, through wearable technology such as a smart watch
Yes, through another way (please specify)
No
I'm not sure

15) **Have you ever used any form of technology to manage your health outside of your respiratory condition?**

Yes, please specify No I'm not sure

16) **Would you be motivated to use technology to manage your respiratory condition if you knew that the data could then be viewed by your clinician to provide you with more personalised care?**

Yes, if the technology was right for me
Yes, even if I was not confident with the technology I would try to learn
No, please specify why
I'm not sure

17) **How often would you be willing to record data about your respiratory condition for self-reflection or sharing with your clinician?**

Once a day, if it was quick to do
Once a day, I would set aside time to do it
Over an agreed period of time decided by my clinician
Only on days where my symptoms were particularly good or bad
Once a week
A few times a week
Never, please specify

Appendix K

Chapter 6: Participant Information Sheet and Consent Form

This section provides the participant information sheet used to recruit the COPD patients for Chapter 6.

Participant Information Sheet

Project Title: How Are You Today
Researchers: Helena Tendedez, Roisin McNaney, Maria-Angela Ferrario
Principal Investigator: Roisin McNaney, Lecturer in Digital Healthcare Technologies School of Computing and Communications, Lancaster University.

About the research and the team
Connected Health Cities is a project designed to unite local health data and advanced technology to improve health services for citizens in North West England. As part of this project, at Lancaster University, we are focused on understanding how people with chronic obstructive pulmonary disease (COPD) self-manage their condition using self-management technologies, such as through mobile phone health apps. We are interested in participants' experiences and perceptions of self-managing using a mobile health application that has been developed by Intelesant Ltd in partnership with [anonymised] (NHS). The researchers in this team are part of the School of Computing and Communications at Lancaster University working on a PhD project that is part of Connected Health Cities. The researchers conducting this study have full insurance cover through Lancaster University.

Why have you been approached?
You have been approached to take part in this project because you have some understanding of chronic obstructive pulmonary disease (COPD) or other respiratory conditions, the care of these conditions and the lives of people affected by the condition. For this reason, we would like to invite you to take part in our study that looks at how people with COPD can self-manage their condition through technology.

Your participation
This project involves using a mobile health smartphone application as a personal symptom diary for 4 weeks alongside your pulmonary rehabilitation involvement at [anonymised]. The smartphone application that you will be using has been developed how Intelesant Ltd in partnership with [anonymised]. The mobile health application will ask a series of five questions each day relating to your symptoms for you to answer. This will generate a diary entry each day on your smartphone. You will have the opportunity to contact the researchers during or after the study, face to face or via email, for any reason.

Your participation in the project can be outlined in three stages, and the project will run alongside your usual pulmonary rehabilitation programme. This project will not change the way in which you receive your usual care.

***Stage 1**:* At the start of the study, the researchers would like to interview you to understand your experiences living with a respiratory condition and perceptions of using technology to self-manage. The interview will last approximately 30-60 minutes. After this interview, you will begin using the mobile phone application to self-manage your condition for 4 weeks. Once you start using the mobile phone app, you will have access to help and support in using it from a dedicated team at Intelesant Ltd. They will describe the app's Privacy Policy and Terms and Conditions to you. You will also have the researchers' telephone number and email address should you have any questions about the research. After this interview, you have two weeks to decide if you wish to withdraw from the study. There is no consequence to withdrawing from the study.

***Stage 2**:* Two weeks into the use of the smartphone app, the researchers would like to telephone you to ask how you are finding the process of using the application to self-manage your condition, and will answer any questions you have about the research. This telephone call will last approximately 20-30 minutes.

Stage 3: After four weeks have passed, you will be at the end of the study. The researchers would like to invite you to a closing interview where you will discuss your diary entries and experiences with the researcher and a COPD nurse. This meeting will solely be to discuss your diary data and experience, not your personal health records or any further aspects of your care. The meeting will be held at a clinical site. You will open the diary app on your phone and you will be discussing your experience of logging your symptom data on an app and discuss any challenges that were encountered. This interview should last between 60-90 minutes.

What happens with the app after the study?
You are free to decide whether you wish to keep the How Are You Today app on your phone and continue using it under the guidance of your community team, or you may choose to delete the app. If you decide to delete the app, both the app and the data accumulated throughout the study will be deleted from your smartphone. If you want further information about this, please contact the researchers or Intelesant Ltd, who can give you the relevant advice. Please note after the study has commenced, if you wish to seek advice on the app, you should contact Intelesant Ltd or your community team.

What does 'Informed Consent' mean?
Before the study commences, you will be asked to sign a consent form to confirm that you have read and received this information sheet and that you are willing to volunteer in this research. You do not have to take part in this study if you do not want to. You have the right to terminate the interview at any point and you are not obliged to answer questions if you do not wish to. You may withdraw from the research without any negative consequences. If you wish to withdraw from this research, please do so within two weeks of the interview, so that the interview material can be excluded from the analysis.

Recording sound
We would like to take audio recordings of the interviews. These audio recordings will be transcribed. Parts of the recordings may be used in publications, such as newspapers, written reports, public presentations, and on the Lancaster University website and respective social media channels. Your name, email or contact addresses will not be used without your explicit

consent. In addition, we are committed to withhold any data that could be used to identify you, such as employer name, address, etc. Therefore, no one will be able to identify you.

Confidentiality and anonymity
All information collected from you will be treated with confidentiality. This means that only the research team will have access to any of the raw information that can be specifically associated with you. Any information that is shared beyond this team will be anonymised. Your name and address will be removed, and we will use a pseudonym to refer to you instead. This will apply to any publication or presentations or any discussions with other colleagues in the University. Data that can be used to identify you will also be removed. We will keep personal details (such as your name and contact email, if you provide this) and research content (e.g. interview transcriptions) in separate encrypted and password protected files.

How will the data be used and protected?
We will treat data that you have provided in accordance with the Data Protection Act 1998. This means that any personal information stored in physical format (paper, readily playable recordings) will be stored in a locked filing cabinet in a locked office in Lancaster University premises. Any personal information that is stored electronically will be stored on a secure and password protected server. Any personal information that is transported electronically on a mobile device (such as a laptop) will be encrypted and/or password protected. The information collected will be used to inform the development of further research and may be included in publications, presentations and PhD theses. Only anonymised information will be retained indefinitely for on-going research purposes. We will keep the raw data for up to 10 years after the data is collected, after that, the data will be destroyed.

Who has reviewed the project?
This study has been fully reviewed by the Faculty of Science and Technology Research Ethics Committee. If you have more questions please contact
Helena Tendedez
School of Computing and Communications,
Room C20, C Floor,
InfoLab21,
Lancaster University, Lancaster LA1 4WA,

Or via email at h.tendedez@lancaster.ac.uk or telephone

Issues or complaints
If you have any concern about this study wish to speak to someone outside study, you may contact: Prof. Nicholas Race, Director of Research, School of Computing and Communications
D33, InfoLab21,
South Drive, Lancaster University,
Lancaster LA1 4WA,
UK Tel: +44 (0)1524 510123
Email: **n.race@lancaster.ac.uk**

Participant Consent Form

Project Title: How Are You Today

Name of Participant: _____

Pseudonym to be in research: _____
(Please leave blank if you prefer the researchers to select a pseudonym)

The purpose of this consent form is to check that you understand what till be required of you, if you agree to take part in this research, and how any information you give will be used in the study.

1. I confirm that I have read and understood the Participant Information Sheet for the above study. ☐
2. I have had the opportunity to consider the information, ask any questions about the research and have had these questions answered satisfactorily. ☐
3. I understand that I have the right to withdraw, without giving any reasons for this, at any point during the study. ☐
4. I agree for any interviews I give to be audio recorded. ☐
5. I agree that any quotations from what I say during an interview can be used in publications. I understand that my quotations and audio recording will be used anonymously. ☐
6. I understand that any personal data I provide will be retained and processed by the researcher in accordance with the Data Protection Act 1998. ☐
7. By providing contact details, I understand that I will be contacted further by the team with updates about the study. ☐
8. I agree for my GP to be notified by [anonymised] that I am taking part in this study. ☐
9. I agree to participate in this study. I understand that my participation is voluntary. ☐

Participant email/phone number: _____

Participant's signature: _____

Researcher's signature: _____

Date: _____